EXPLAINING PROFESSIONAL BEHAVIOR WHEN DEVELOPING CARE PATHWAYS FOR NEURODEVELOPMENTAL DISORDERS

SEEING COMMON PROBLEMS AS PROBLEMS OF COMMONS

Linnæus University

Carl von Linné, botanist.

"Omnia mirari etiam tritissima"

Find wonder in everything, even the most commonplace.

Neither of the authors have received and will not receive any commercial support related to this presentation or the work presented in this presentation.

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ACCOUNT IS BASED ON

- Waxegård, G., & Thulesius, H. (2016). Integrating care for neurodevelopmental disorders by unpacking control: A grounded theory study. *International Journal of Qualitative Studies on Health and Well-being, 11*. doi:10.3402/qhw.v11.31987

- Waxegård, G., & Thulesius, H. (2016). Trust testing in care pathways for neurodevelopmental disorders: A grounded theory study. *Grounded Theory Review, 15*(1), 45-58.

- Waxegård, G. & Thulesius, H. *In preparation.* Appropriating in care pathways for neurodevelopmental disorder: Seeing common problems as problems of commons.

FIRST… ”TO!” = SHOE; ”TITI!”= PEEK-A-BOO

What if he showed early signs of an atypical developmental trajectory?

He would, based on current knowledge, benefit best from *early, multi-professional, specialist prevention.*

Much of health care does not offer this today, since the main thrust is still on professional *late specialist treatment delivered by one or two professionals.*

If this was to change, what are the implications for professionals and their strategies, structures, methods? Who decides whether this change will happen?

GIVING IT AWAY

- Care pathways for neurodevelopmental disorders are commons, or common pool resources, in Ostromian terms – for professionals.
- Really complex commons. The *resource* is super-complex and verbal in nature.
- We did not assume this. Data led us there.

WHAT IS THE METHOD?

Classic grounded theory (Glaser).

Qualitiative research method open to multi-level data, capable of processing a large amount of input.

Goal: to create new, useful theory in the social sciences.

Very particular with its philosophical and methodological assumptions.

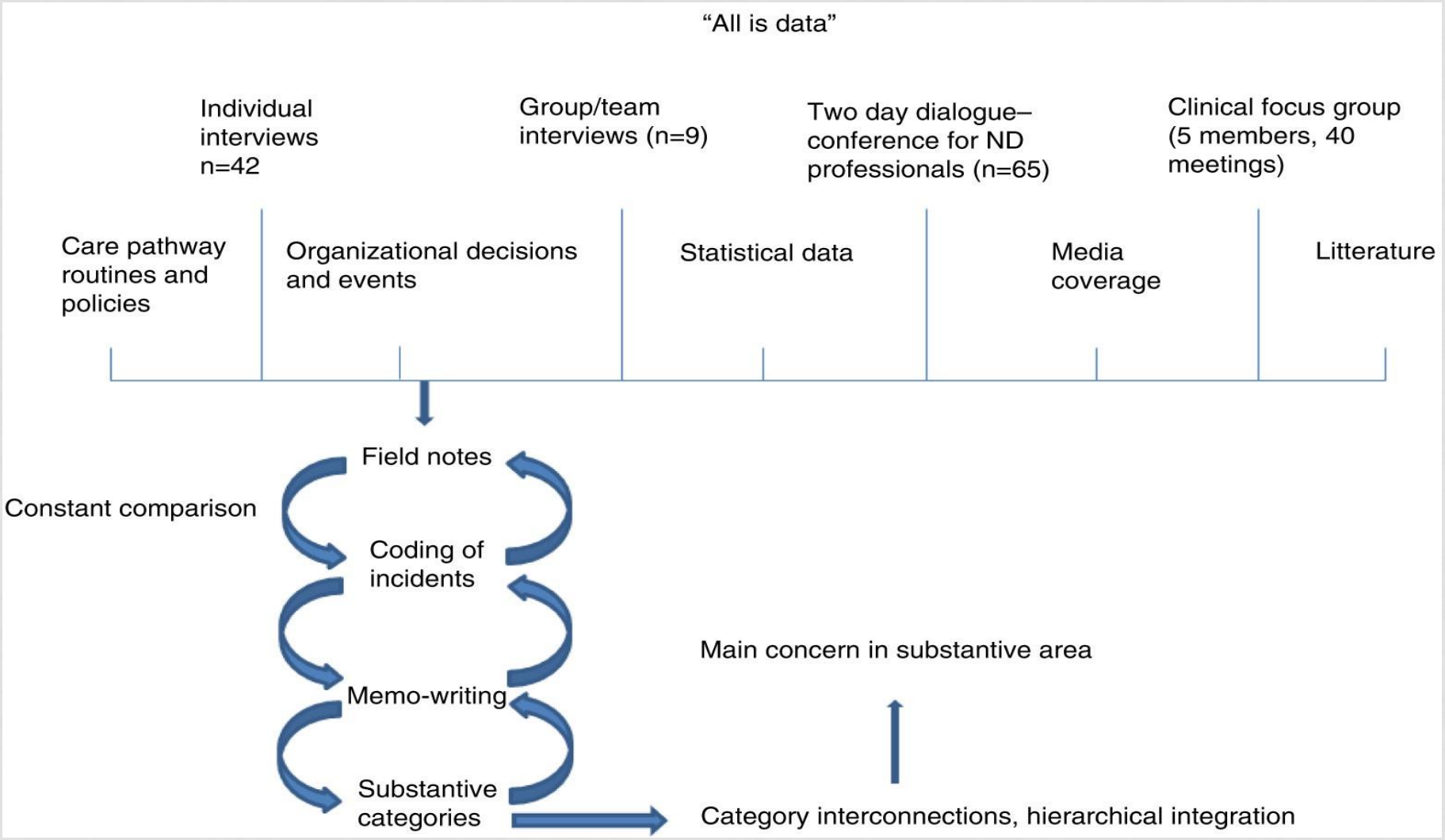
IS CGT COMPATIBLE WITH A CBS-PERSPECTIVE?

- Classic Grounded Theory is compatible with any social science theory – it follows the data.

Furthermore:

- Essentially pragmatic view of methodological justification.
- Evaluative criteria: fit, workability, relevance and modifiability
- Idiosyncratic rather than nomothetic approach.
- Conceptualizes on-going behavior in context.
- Monistic stance.
- "Core category": high scope term orienting a listener towards a central domain.
- Generalizing: a concept or a theory being useful in more than one case, rather than the cases being descriptively or topographically "the same"
- Obviously, several analytical goals are **not** shared.

WHAT ARE THE DATA?



Main data sampling:	Interviews with professionals, individual + group. Dialogue conference about ND care pathway. Project group meetings. Care pathway routines and policies. National outlook to identify similar projects for the sake of comparison. Statistical data.			Stakeholder actions. Implementation behaviour. Media coverage. Literature review.		ND experts. ND professional from unrelated ND care pathways. Peer debriefing.	
Theory concept(s) in focus:	Health care logistics, industrial metaphors. Patient flows.	Sprawl and fragmentation. Lack of professional coherence in ND care pathway.	ND complexity identified as main concern. Pluralistic dialogue (emergent fit). Trust testing.	"Problematic Unpacking". Open-ended or "pragmatic" vs doctrinaire unpacking.	Specifying patterns of sub-concerns: • Expanding constructive life space • Squeezing • Ideologizing • Isolating	"Unpacking control" stated as core category. Core property of Unpacking control is to allow up- and/or down regulation of ND care complexity as a response to overhwelming ND complexity.	
Chronological study timeline:	Region project start up.	Preliminary project report presented.	Main project report presented.	Implementation of project conclusions in ND care pathway (main case). Theory integration. Contact with two other ND care pathways established.			Follow-up interviews to validate theory. Situating findings in literature.
	2009	2010	2011	2012	2013	2014	2015

DEFINING NEURODEVELOPMENTAL DISORDERS

- Following the DSM-5, include ADHD, ASD, IDD, and more.
- Early emerging syndromes associated with atypical functioning with respect to social, attentional, language, motor, executive, academic, occupational and relational capacities.
- Genetically, neuroanatomically, behaviorally, functionally, ethically (e. g. variation vs disorder) complex; highly "comorbid"…
- Loads of research, no definitive cure, no definitive understanding.

(e. g. APA, 2013; Akutagava-Martins, Salatino-Oliveira, Kieling, Rohde, & Hutz, 2013; Chen, Peñagarikano, Belgard, Swarup, & Geschwind, 2015; Bishop & Rutter, 2009; D'Souza & Karmiloff-Smith, 2017; Feldman & Reiff, 2014; Jones, Gliga, Bedford, Charman, & Johnson, 2014; Lai, Lombardo, & Baron-Cohen, 2014; Thapar, Cooper, Eyre, & Langley, 2013)

DEFINITIONS OF CARE PATHWAYS

- **In Scandinavian contexts often called *chains of care:***

"*coordinated activities within health care, interlinked to result in a good outcome for the patient.*" (Åhgren, 2001, p. 29).

- **Alternatively, as the general activity of coordinating care. The Agency for Healthcare Research and Quality (2014):**

"*Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.*"

DEFINITIONS OF CARE PATHWAYS

- **The European Pathway Association:**

"*A complex intervention for the mutual decision making and organization of predictable care for a well-defined group of patients during a well-defined period. Defining characteristics of pathways include: an explicit statement of the goals and key elements of care based on evidence, best practice and patient expectations; the facilitations of the communication and coordination of roles, and sequencing the activities of the multidisciplinary care team, patients and their relatives; the documentation, monitoring, and evaluation of variances and outcomes; and the identification of relevant resources.*" (Vanhaecht, 2007).

The UK NHS:

- "*…both a tool and a concept that embed guidelines, protocols and locally agreed, evidence-based, patient-centered, best practice, into everyday use for the individual patient*" (Evans-Lacko, Jarrett, McCrone, & Thornicroft, 2008).

DEFINITIONS OF CARE PATHWAYS

- "In spite of a substantial amount of research on issues of care coordination, definitions and theoretical frameworks have proliferated and a clear theoretical understanding of key factors is lacking." (Van Houdt, Heyrman, Vanhaecht, Sermeus, & De Lepeleire, 2013; Van Houdt, Sermeus, Vanhaecht, & De Lepeleire, 2014).

- **Common to most definitions is that they trace their origin to industrial processes that have been adapted to a health care context.**

DEFINING COMMONS AND CPR:S

- Commons, seminally conceptualized by Hardin (1968, 1994, 1998), and Ostrom (1990/2015) see also Ostrom,1999, 2000, 2010; Ostrom, Burger, Field, Norgaard, & Policansky, 1999; Walker, 2015) present a social dilemma: *rationality at the individual level is irrationality from a collective viewpoint*.

- A farmer that puts an extra cow on the common meadow gets the whole return from selling the cow, while the loss of sustainability in the common due to over-grazing is shared by all farmers.

COMMON POOL RESOURCES

- Commons can be operationalized as *common pool resources* (CPR) (Ostrom, 1990/2015).
- Holds a natural or man-made resource, neither entirely privatized nor monopolized.
- The resource is mined, or *appropriated* (Ostrom, 1990/2015, p. 30) by a set of so called appropriators.
- Subtractability of use. Sets it apart from *public goods,*
- Excluding people from using a CPR = difficult and costly. Sets it apart from private goods, where ownership of the resource is clear, exclusive, and legally protected (McGinnis & Ostrom, 2008).

THE THEORY

Professional main concern/challenge/problem when working in the ND care pathway:

ND-RELATED COMPLEXITY

EXAMPLES OF "COMPLEXITY" AT THE DATA LEVEL

- Direct or indirect references to complexity:

"It can be sort of heavy, when most assessments are complex, when there is no real clarity at all, and when all observations are pointing in different directions, and there is just sprawl. That can be confusing . . . as well as difficult to convey to parents."

"Working with ND is very different [from pre- vious job as a ward nurse]. . . You have to think more for yourself and find your own solutions. It is difficult, really difficult! You have to be much more well prepared for each child that you see, what earlier information there is and so."

Also: Cooperative failures due to not taking complexity into consideration, *underconceptualizing; lack of dialogue.*

A GLIMPSE OF COMPLEXITY: RULES

- ND professionals are subject to rules, norms as well as shared strategies (ADICO) (Ostrom, 2005, pp.137-174) in the form of:
  - health care legislation; ethic codes of the respective professions; clinical guidelines concerning ND and other co-occurring disorders formulated at different levels (international, national, regional and/or local); budget keeping; the specific rules of various clinical frameworks such as behavior analysis, attachment theory or systemic approaches; locally negotiated routines concerning referral practices; political decisions at various levels; workplace culture; management philosophy; the specified boundary conditions between clinics, teams and care levels; ad hoc solutions put in place when existing rules do not solve the problems at hand; the values embraced by the health care/CPR provider; regulations concerning access to working material such as tests and medical equipment; and more.

RESOLUTION STRATEGY 1:

Unpacking control

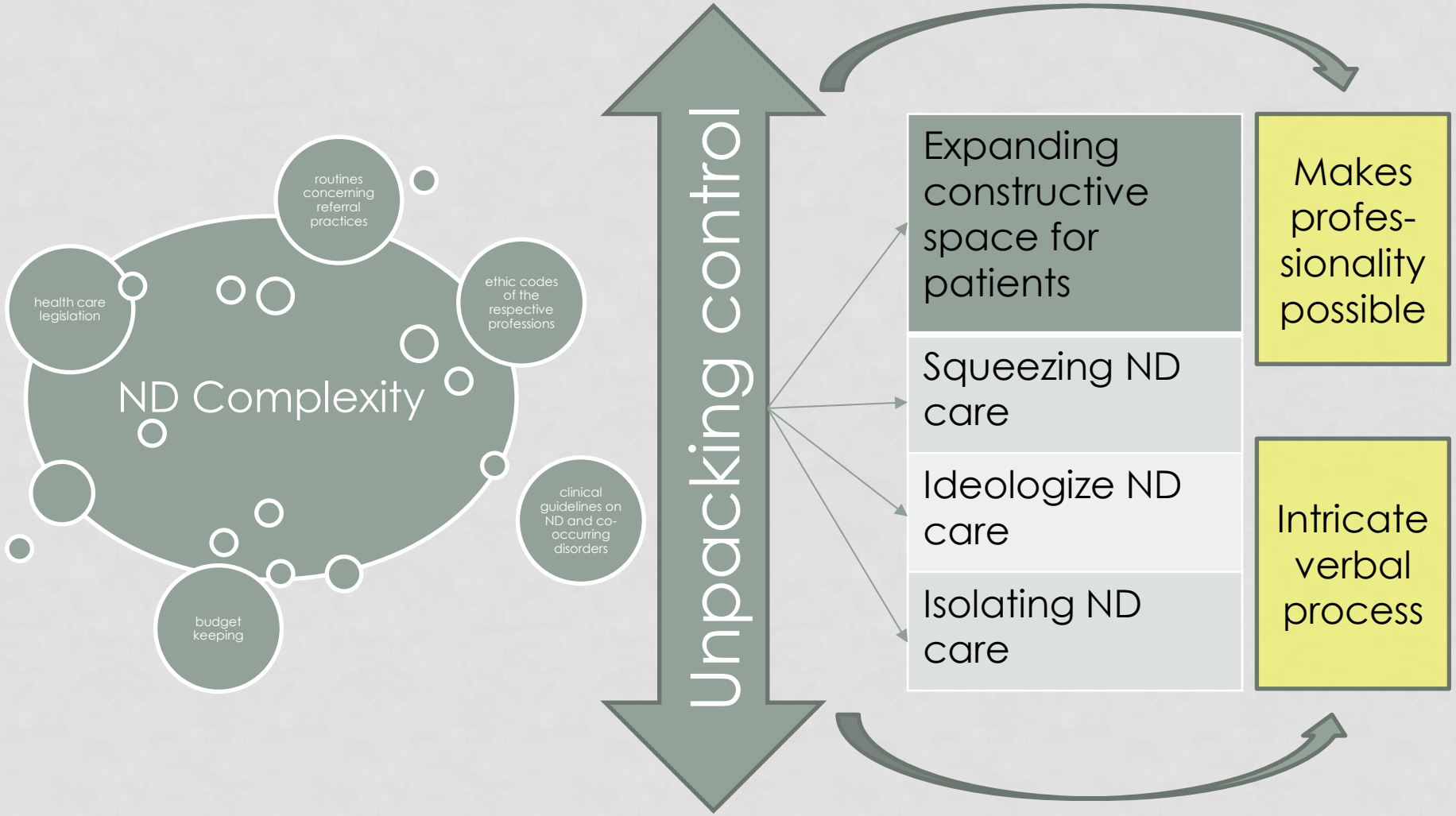
Establishing professional control over strategies, structures, and methods to define ND-problems.

- A multi-faceted professional activity pattern, used to crunch, or regulate, ND-related complexity.
- High abstraction-concept: includes a lot of the relevant variance in the data.

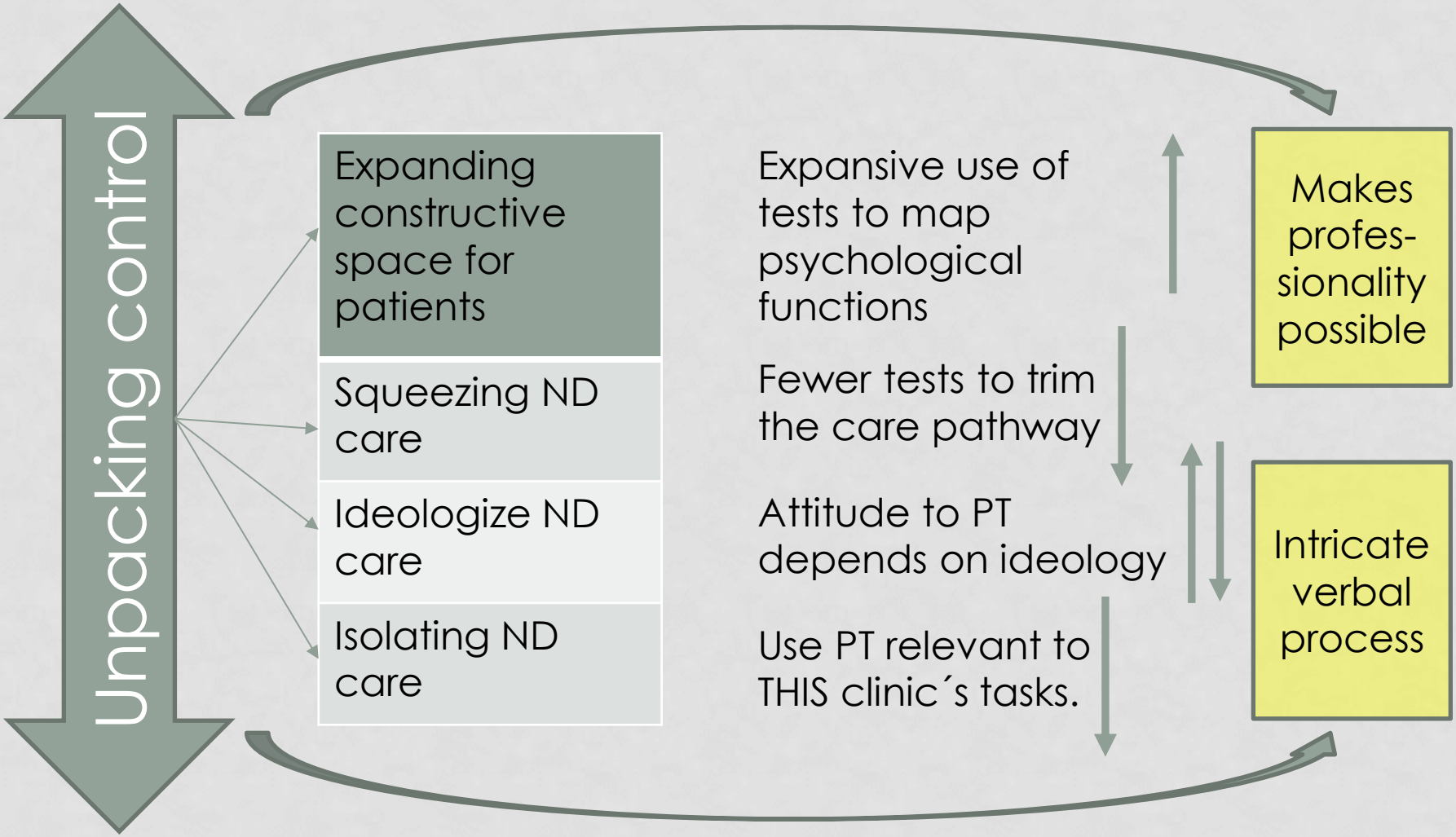
UNPACKING CONTROL…

…permits professionals to choose type and level of complexity allowed to emerge when formalizing ND-problems.

CONCEPTUALIZING UNPACKING CONTROL



THE EXAMPLE OF PSYCHOMETRIC TESTS

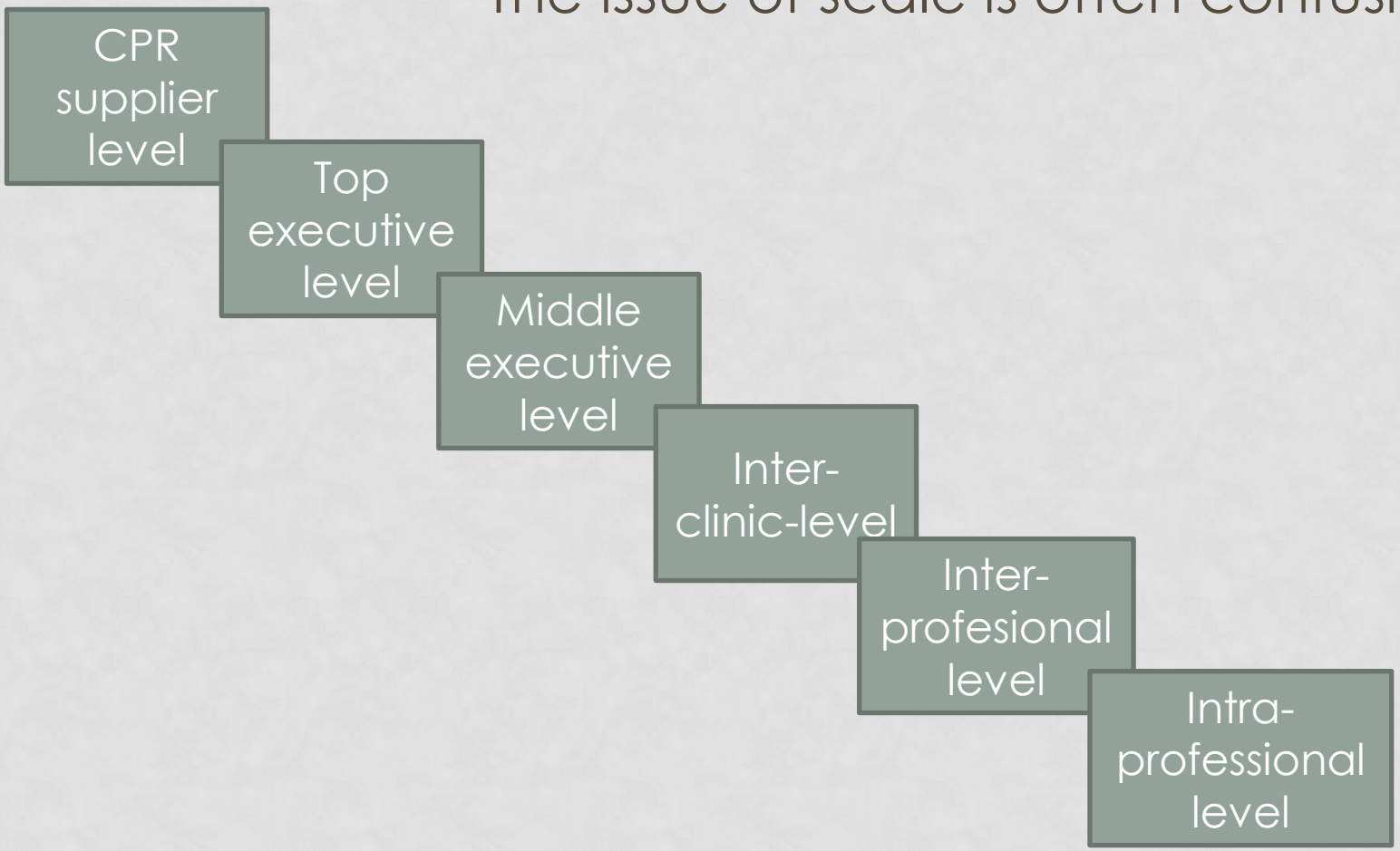


UNPACKING CONTROL…

- …is best understood in the light of professions theory (e. g. Abbott, 1988).
- Solving complex tasks with autonomy is a key property of professionalism.
- UC is similar to Abbott's term jurisdictional control, which is to successfully claim ownership of a professional area containing ''human problems amenable to expert service'' (Abbott, 1988, p. 35).
- UC contributes to the understanding of how professionals uphold jurisdictional control in a changing healthcare landscape.

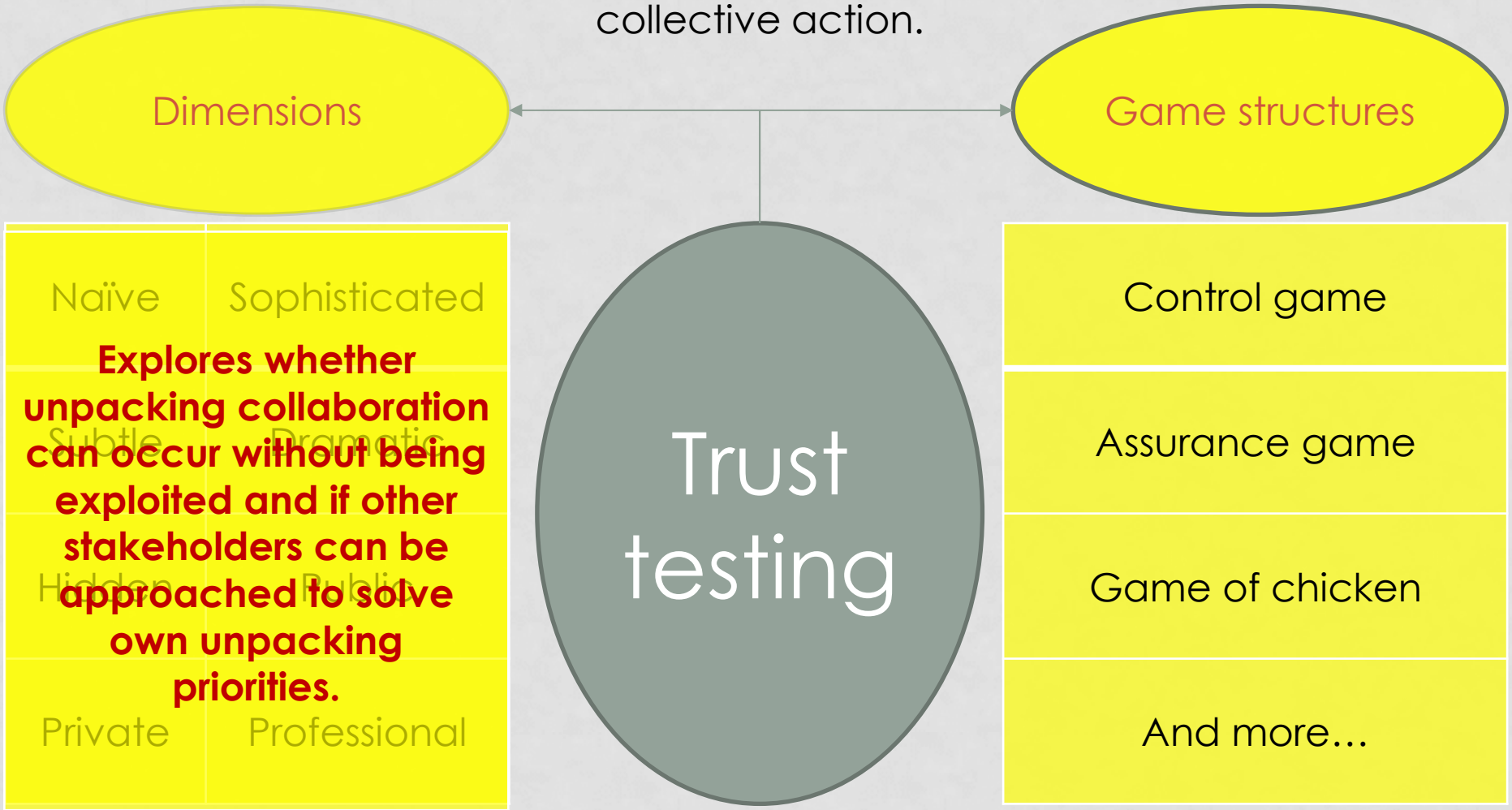
UC RELEVANT AT ALL LEVELS

- The issue of scale is often confusing!



RESOLUTION STRATEGY 2: TRUST TESTING

Trust testing regulates possibilities to integrate the care pathway through collective action.



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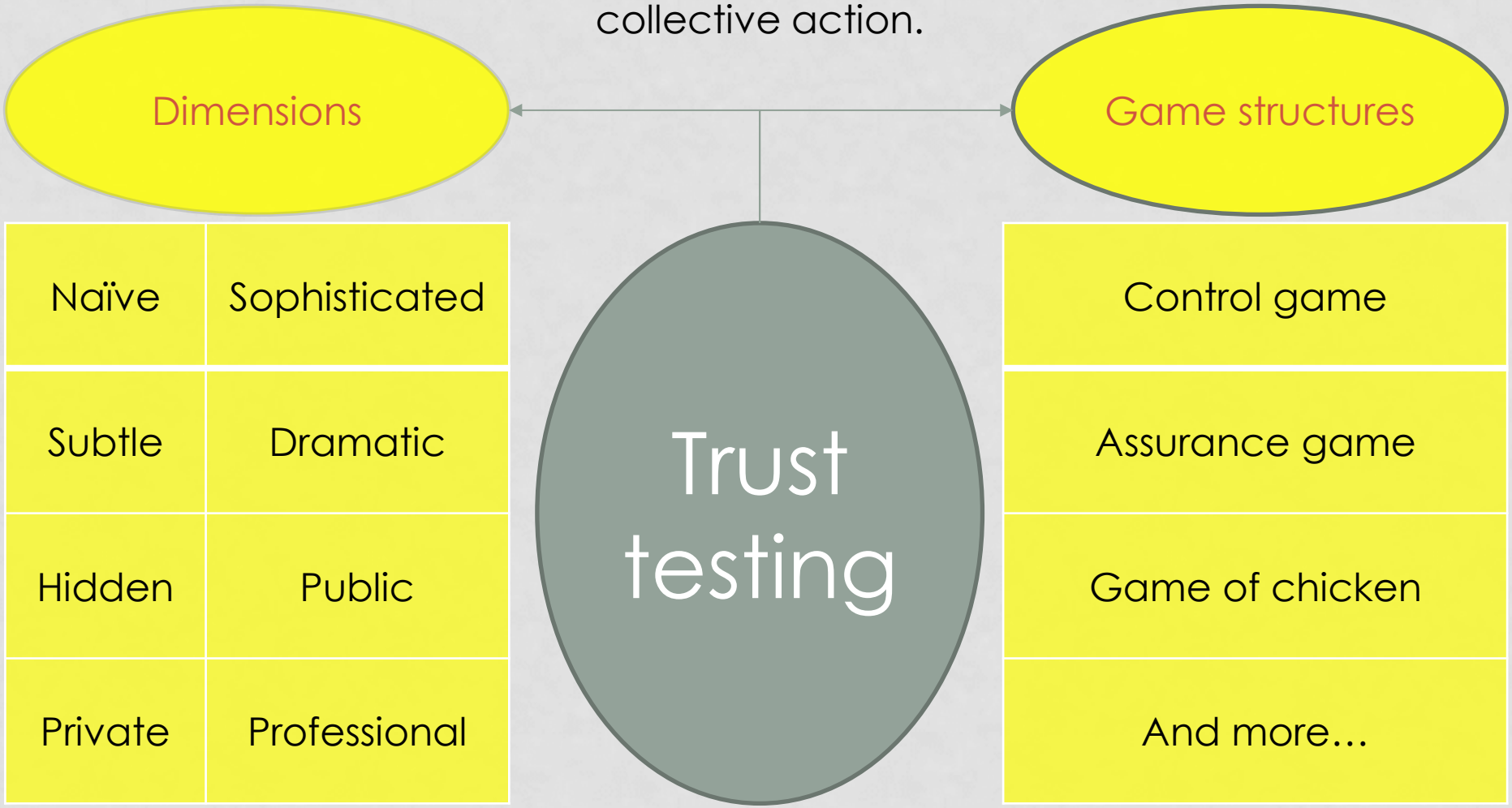


TRUST TESTING IS…

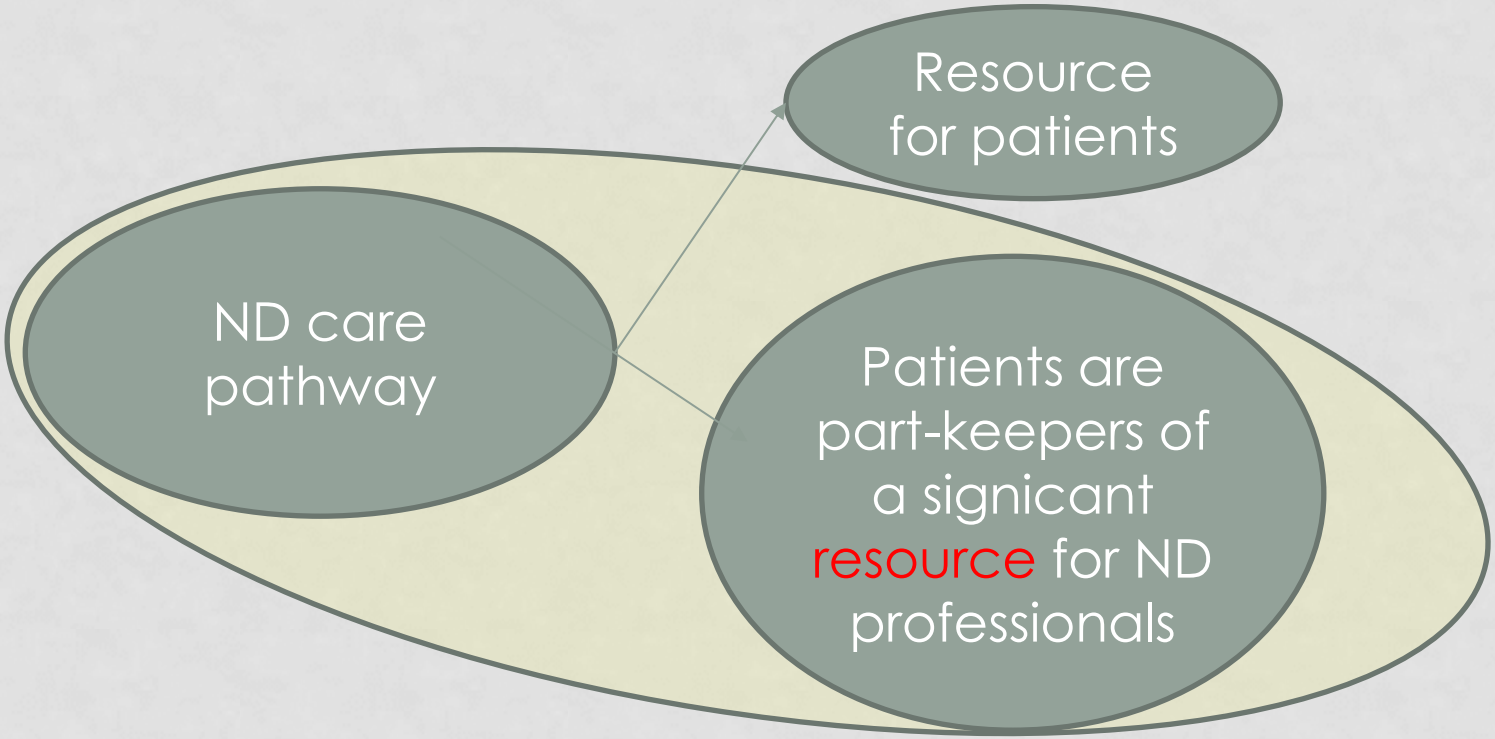
…best understood in the light of social dilemma research and game theory:

- No one game dominates and the set-up is typically asymmetric (Bornstein, 2008:) individuals play against groups, groups against groups and individuals against individuals, all play against the intricate nature of ND.

THE LARGER PICTURE

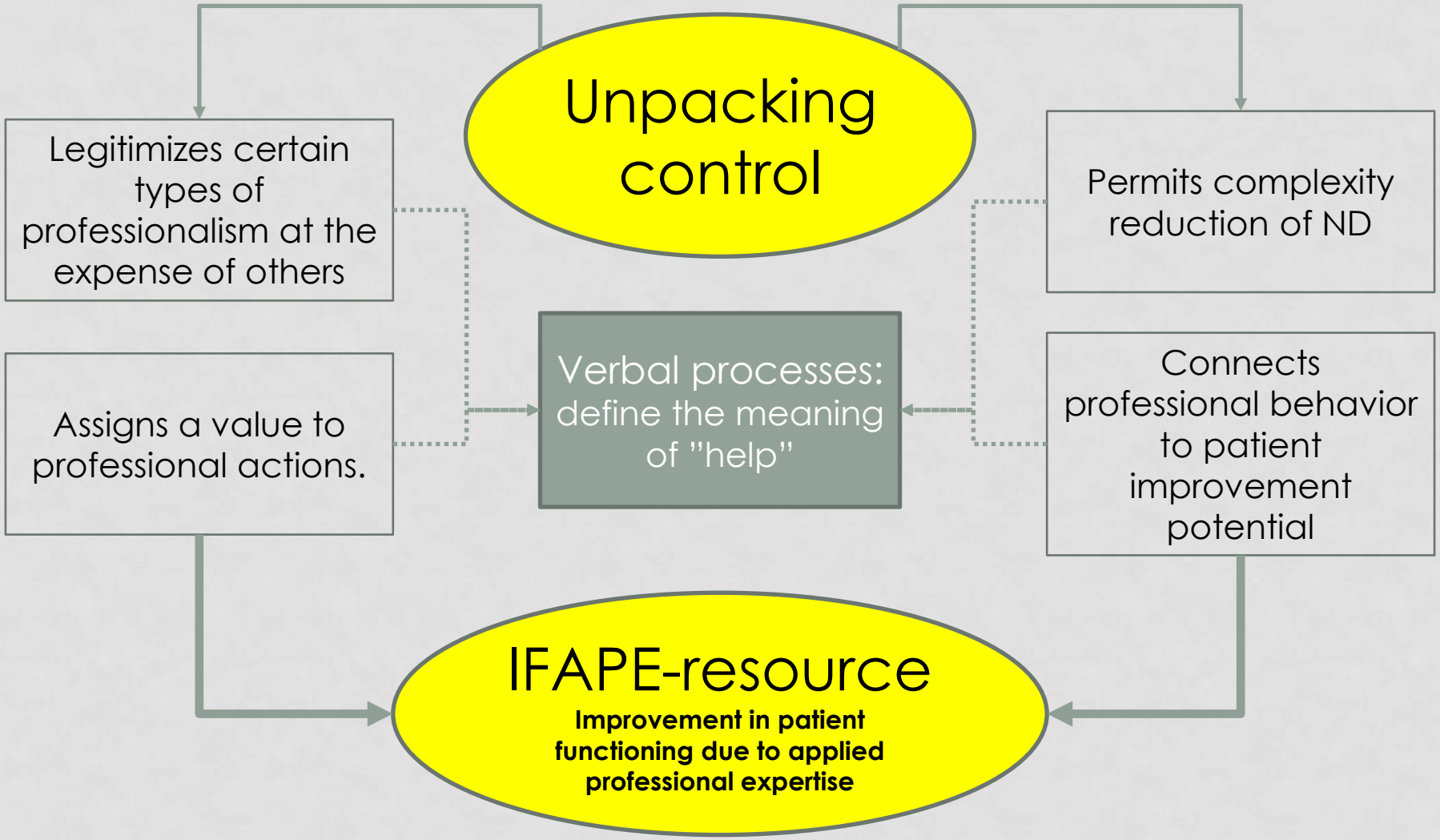
- A set of semi-autonomous, interdependent professional stakeholders, continually exploring trust-issues to decide on collective or egoistic action.
- Boundary rules to ND care pathways apply, that are largely upheld by professionals themselves.
- The ND care pathway relies heavily on operational-, collective choice- and constitutional choice rules to function properly.
- The target for this activity is patient improvement by professional means….
- …for conditions so multifaceted in nature that several professions are needed to manage them.
- This is all taking place in a structure (ND care pathway) that is markedly common-like.

CONTEXTUALIZING UC & TT



- UC & TT jointly function to secure professionals' access to a common pool resource.

THE IFAPE-RESOURCE



UC AND RELATIONAL FRAME THOERY

- Stated technically: the professional system provides a myriad of contextual cues, relational as well as functional (C_{rel} and C_{func}) with regard to ND patients´ behavior.

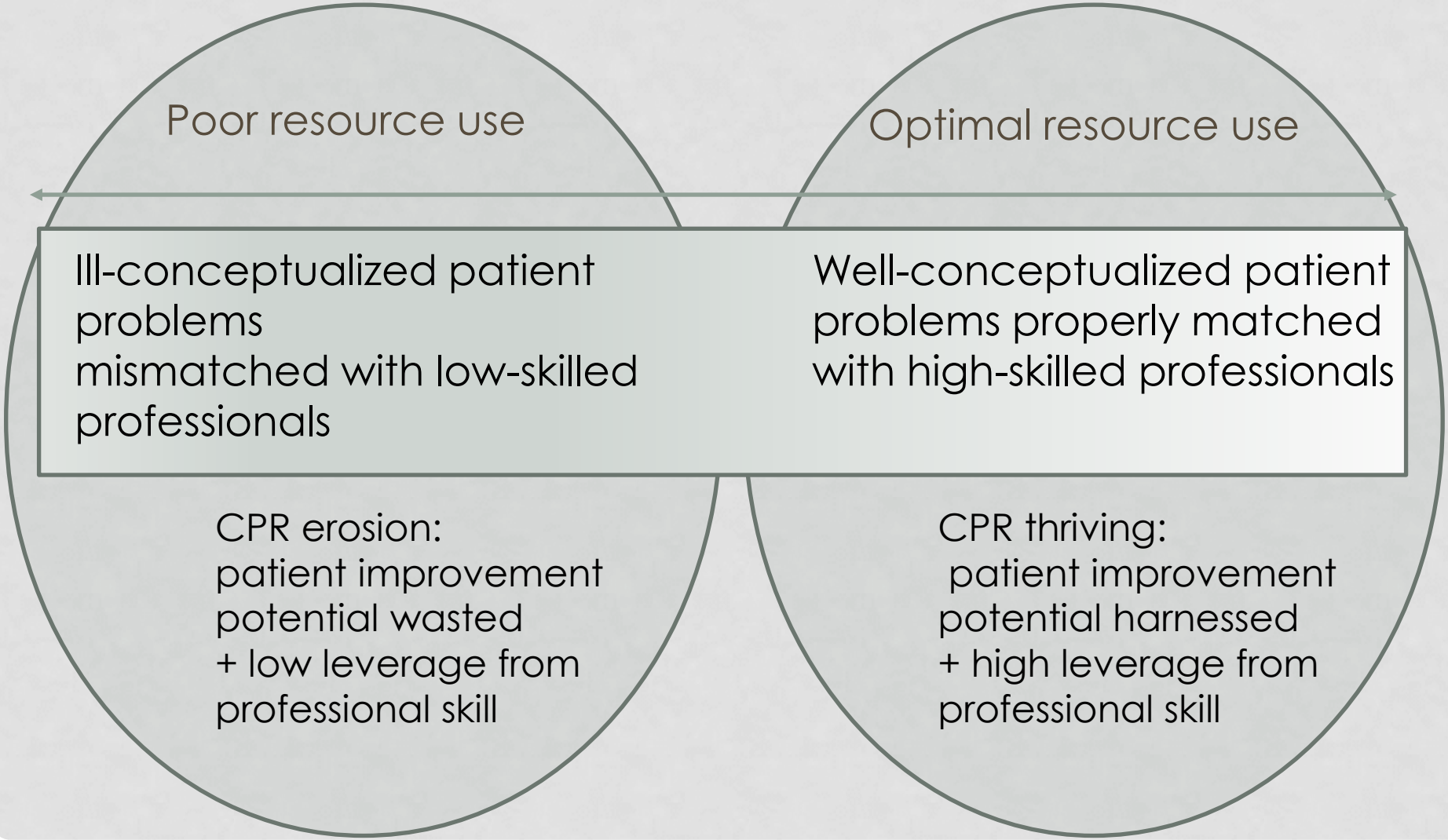
- Controlling the provision of these cues both offers a solution to inherent ND complexity and strengthens professional legitimacy in ND care pathways.

- Unpacking control, then, originally defined as the wish to gain professional control over care structures, methods and strategies used to define ND in patients, functions to collectively or unilaterally establishing consistent relational framing between a preferred professional practice and later interactions with patients in order to materialize IFAPE.

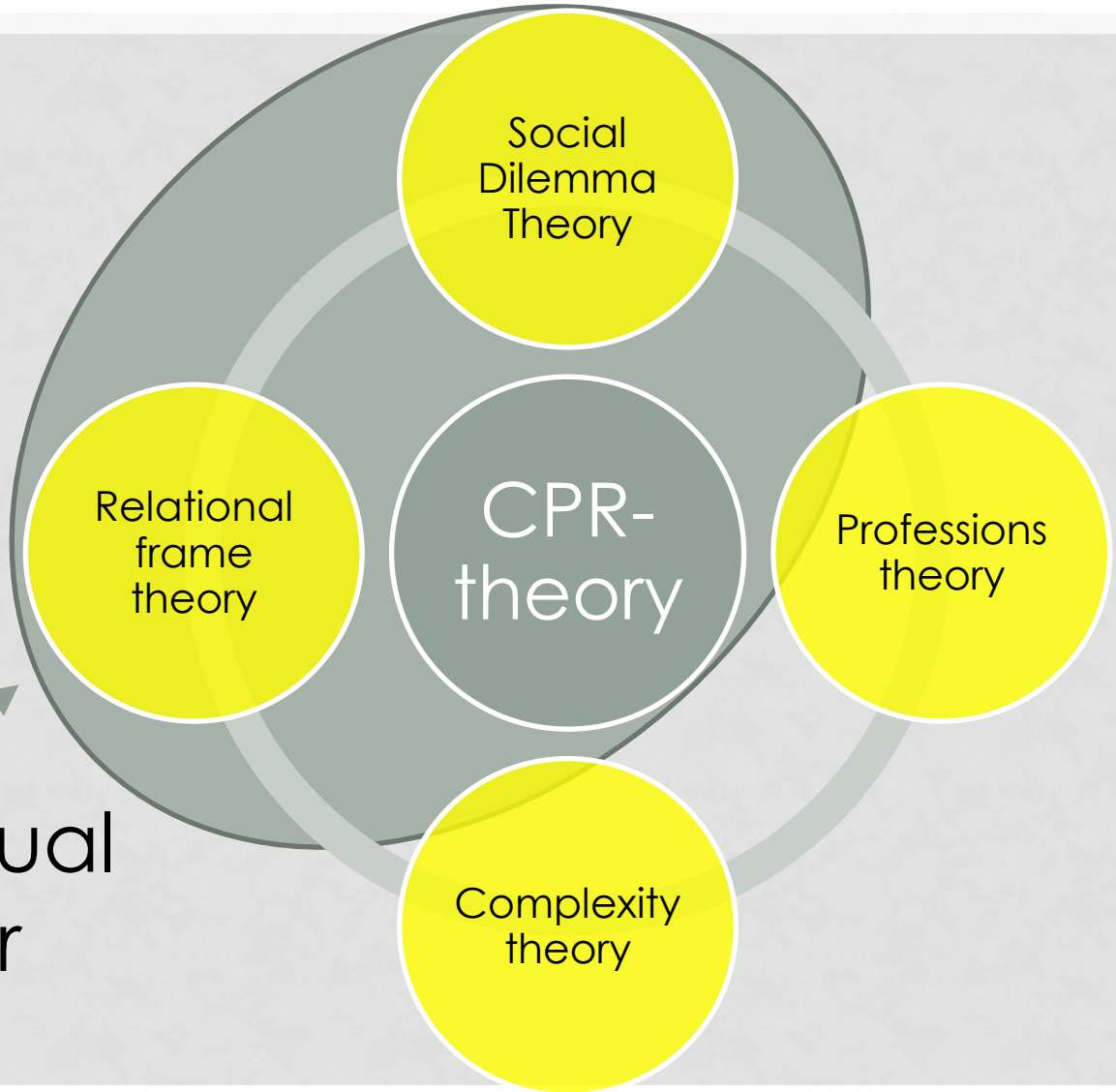
THE MDML-FRAMEWORK

- The MDML-framework as outlined by Barnes-Holmes, Barnes-Holmes, Hussey & Luciano (2016), adding the dimensions of coherence and degree of derivation to ND-related verbal behavior in professionals seems particularly promising to increase the precision of our observations on this aspect of ND unpacking control.

APPROPRIATION AND PROVISION PROBLEMS



SUGGESTED THEORETICAL FRAMEWORK FOR "SOLVING" CPND:S

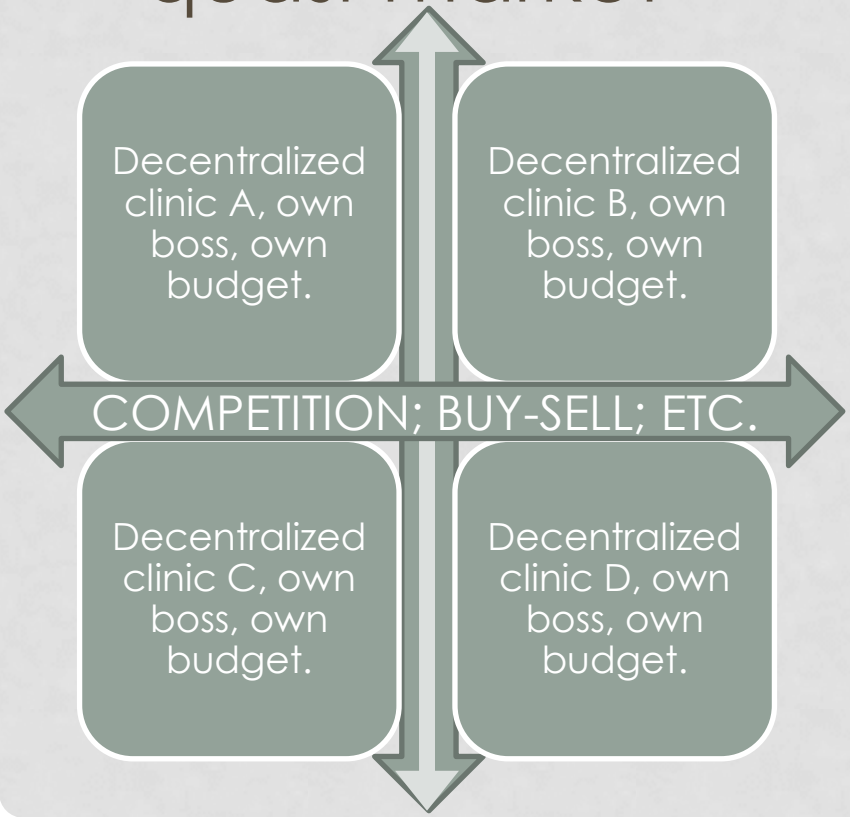


PREDICTIONS

- Non-qualified people cherry-picking aspects of psychological or general mental health knowledge to gain their living threatens CPR boundaries and appropriation rules and will result in attempts to exclude them from the resource.
- There will be competition about IFAPE access *inside* the CPR. May explain professional tribalism within ND care pathways and other mental health care pathways.
- Topographically similar patient behavior will function differently as contextual cues for professionals depending on the professional´s learning history and motivational state.
- Patients with less perceived improvement potential will be less attractive to professionals. ND patients are at risk of less professional investment.
- Professionals not tending to their professional competence will face punishment by colleagues, since they share pay-off but invest less to receive it.
- Very competent professionals pose a threat to status quo, by introducing new techniques and knowledge in the appropriation process that is not available to all professionals.
- Successful ND care pathways will be based on dialogue and inclusion of most concerned professionals and performed with clear bottom up-features. Research supports this notion(Ham, 2003; Ahgren & Axelsson, 2007).

PREDICTION II: THESE MODELS ALONE WILL NOT SAVE THE DAY

- The New Public Management quasi-market



- The professional bureaucracy

INFLUENCE I: OSTROM´S 8 PRINCIPLES

- **Commons-theorists have delineated principles for successful governing of common pool resources (e. g. Agrawal, 2002, pp. 47-70). In the case of Elinor Ostrom (1990/2015, p.90), these are:**

1. Clearly defined boundaries with respect to who can appropriate and to the boundaries of the CPR itself.
2. Congruence between appropriation and provision rules and local conditions.
3. Collective choice-arrangements, meaning that most people involved in the CPR have the chance to influence operational, day-to-day rules.
4. Monitoring. Monitoring of the CPR is in place and the ones who monitors are accountable to, or are, the appropriators.
5. Graduated sanctions. When any stakeholder free-rides or break operational rules s/he faces effective sanctions.
6. Conflict resolution mechanisms. These should be of low cost and with rapid access.
7. Minimal recognition of the rights to organize. Appropriators must not be prohibited to act jointly by external authorities.
8. Nested enterprizes. For larger CPRs, they should be successfully nested into the larger structures and multiple layers of society which impacts provision, supply, rules, conflict resolution, and more.

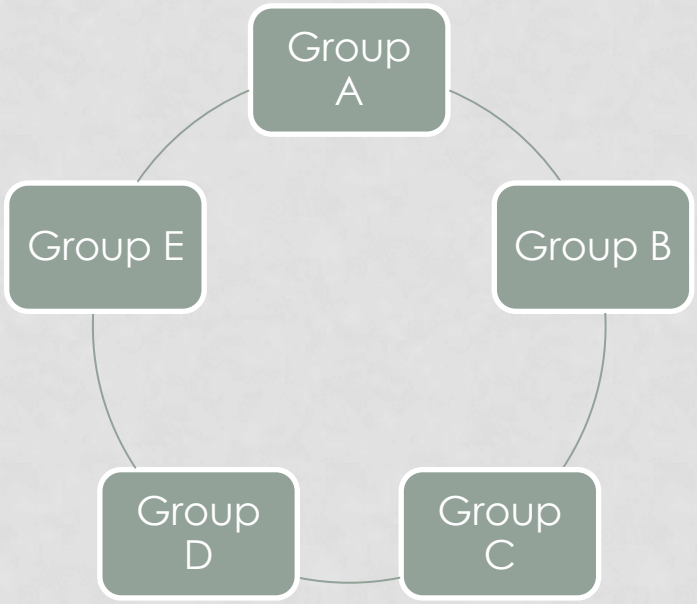
INFLUENCE II

- The PROSOCIAL-framework (Combining ACT matrix & Ostrom's design principles).
- https://www.prosocial.world

+ add the aspect of Unpacking control, professions theory, and ND complexity on content level.

+ measure process- and quality indicators.

= Research intervention for NDCP:s.



FUTURE RESEARCH SUGGESTIONS

1. Explore how nesting of ND CPR into other societal structures impact the CPR.
2. Micro-level studies based on IAD-perspective exploring action situations, game structures, local rules, monitoring and sanctions, and more.
3. Exclusively explore the function and formation of CPR rules and their impact on the CPR.
4. Probe the nature of the IFAPE resource itself. Since ND is not yet completely understood, the same goes for the improvement potential in patients that suffers from ND, as well as for what kind of professional expertise that will ultimately prove the most efficient to apply to alleviate suffering.
5. Explore CPR:s made out of human interactions, becoming interactive, creating a need for more complex theoretical models.
6. Explore polycentric governance (Ostrom, 2010; Addy, Poirier, Blouin, Drager, & Dubé, 2014) in relation to health care and ND care pathways,
7. Evaluate the PROSOCIAL framework to the develop ND care pathways.
8. Explore mechanisms of multi-level group selection (e. g. Field, 2008; Wilson, Ostrom & Cox, 2013) to explain occurrences of altruistic behavior between units in the care pathway.
9. Use this social-ecological system to pin down the basic principles for development of complex social systems as reflected on by Wilson, Hayes, Biglan & Embry (2014).
10. Develop "diagnostic ontologies" for ND care pathways in the sense described by Frey & Cox (2015) to come to terms with *the complexity problem, the panacea problem,* and *the scatter problem*.