GROUNDED THEORY REVIEW
An international journal

Trust Testing in Care Pathways for Neurodevelopmental Disorders: A Grounded Theory Study

Gustaf Waxegard, Linnaeus University, Sweden

Hans Thulesius, Lund University, Sweden

2016

Grounded Theory Review, Vol 15 (Issue #1), 45-58

The online version of this article can be found at:

https://groundedtheoryreview.org

Originally published by Sociology Press

https://sociologypress.com/

Archived by the Institute for Research and Theory Methodologies

https://www.mentoringresearchers.org/

Trust Testing in Care Pathways for Neurodevelopmental Disorders: A Grounded Theory Study

Gustaf Waxegard, Linnaeus University, Sweden

Hans Thulesius, Lund University, Sweden

Abstract

Building care pathways for the expansive, heterogeneous, and complex field of neurodevelopmental disorders (ND) is challenging. This classic grounded theory study conceptualizes problems encountered and resolved by professionals in the unpacking—diagnosis and work up—of ND. A care pathway for ND in children and adolescents was observed for six years. Data include interviews, documentation of a dialogue-conference devoted to the ND care pathway, 100+ hours of participant observations, and coding of stakeholder actions. Trust testing explores whether professional unpacking collaboration can occur without being "stuck with the buck" and if other professionals can be approached to solve own unpacking priorities. ND complexity, scarce resources, and diverging stakeholder interests undermine the ability to make selfless collaborative professional choices in the care pathway. ND professionals and managers should pay as much attention to trust issues as they do to structures and patient flows. The trust testing theory may improve the understanding of ND care pathways further as a modified social dilemma framework.

Keywords: Care pathways; neurodevelopmental disorders; ADHD; autism; social dilemma.

Background

In spite of evidence for the need of a more holistic, integrated care pathways for children and youth with neurodevelopmental disorders (ND), including autism spectrum disorders and attention deficit hyperactivity disorder, putting inter-agency care pathways into practice has proved problematic (Evans & Baker, 2012; Kirby & Thomas, 2011; Salmon & Kirby, 2008).

Support for the necessity of cooperation and coordination between professional stakeholders with regard to ND comes from multiple sources such as the experiences of parents and families (King, Cathers, King, & Rosenbaum, 2001; Miller, Condin, McKellin, Shaw, Klassen, & Sheps, 2009; Singh et al., 2010), behavioral genetics, which shows a great deal of overlap between different ND diagnoses (Posthuma & Polderman, 2013; Rommelse, Franke, Altink, et al., 2009; Rommelse, Franke, Geurts, Hartman, & Buitelaar, 2010; Ronald, Larsson, Anckarsäter, & Lichtenstein, 2014; Ronald, Simonoff, Kuntsi, Asherson, & Plomin, 2008), research on comorbidity (Gillberg et al., 2004; Leyfer

et al., 2006; Yoshida & Uchiyama, 2004), the framework of developmental psychopathology (Rutter, 2013c; Schmidt & Petermann, 2009), preventive research and increased awareness of the need for early identification of ND (Daniels, Halladay, Shih, Elder, & Dawson, 2014; Gillberg, 2010; Halperin, Bédard, & Curchack-Lichtin, 2012), high and increasing prevalence rates (Baron-Cohen et al., 2009; Gillberg, Cederlund, Lamberg, & Zeijlon, 2006; Polanczyk, De Lima, Horta, Biederman, & Rohde, 2007; Willcutt, 2012), and the chronicity and multiple life domains affected by ND (Barkley, 2002; Barkley, Fischer, Smallish, & Fletcher, 2002; Rutter, 2013a; Turgay et al., 2012; Wolraich et al., 2005).

The formation of integrated care pathways is no new phenomenon (Campbell, Hotchkiss, Bradshaw, & Porteous, 1998) and is encouraged by governments and health care policymakers across the world. Various theoretical frameworks have been invoked to deal with challenges to integrating care, among these stakeholder theory (Agle et al., 2008; Phillips, Freeman, & Wicks, 2003), complex adaptive systems theory (Brown, 2006; McDaniel Jr, Lanham, & Anderson, 2009), theories of organizational culture (Dodek, Cahill, & Heyland, 2010; Schein, 2006), health care system ecology (Ahgren, 2010), network theory (Mur-Veeman, Hardy, Steenbergen, & Wistow, 2003; Scott & Hofmeyer, 2007), resource dependence theory and institutional theory (Guo & Acar, 2005; Van Raak, Paulus, & Mur-Veeman, 2005). To our knowledge, few of these theories have been employed to analyze ND care pathways. As to ND, different scholars propose different vehicles as the best integrating force to achieve successful care pathways, such as locally agreed professional guidelines (Blew & Kenny, 2006), parent-held documentation (Burgess, 2002), a common code of ethics in the care pathway (Cox, 2012), shared mental models of integrated care (Evans & Baker, 2012) or increased reflective space for professionals (Kildea, Wright, & Davies, 2011). Generally, when implemented, the fate of new programs in health care is uncertain with variable and largely unknown sustainability and fidelity rates (Wiltsey Stirman et al., 2012).

Organizational theorizing about integrated ND care systems is thus in its early stages, relying on generic management theories originally formulated not with ND primarily in mind. Well-developed theories specifically concerned with ND care pathways are rare; indeed, we have found none. In depth studies of individual ND care pathways, such as the one described in this paper, are therefore warranted in order to provide empirical material and inductive contributions to refining health care for one of the largest populations in mental health. Objectives of this qualitative study were to conceptualize the major problems encountered by professionals in the organisation of ND care pathways and to find out how they are resolved.

Methods

Data for this study were collected over a period of approximately six years. The bulk of empirical data come from one Swedish region with a population of 190,000 and the rest from two other Swedish regions. The first author (Gustaf Waxegård) was granted access to the care processes for ND among children and adolescents in his role auditing a nationally funded, 3-year regional health care project of care pathway improvement. The care pathway was thoroughly documented by the authors and then monitored through the project implementation phase and beyond. Data for this study, collected between 2009 and 2015, include 42 individual interviews with professionals, 34 women and eight

men from 24 to 71 years old. Fifteen were psychologists, eight physicians, five nurses, three social workers, three occupational therapists, two physiotherapists, two special educators, one health care developer, one economist, and two professional patient representatives. Additionally, we did nine group interviews with teams concerned with ND. A two-day dialogue conference on ND care pathways for health professionals, managers, health care developers, and health care politicians in the region was arranged and documented, where 65 participants jointly analysed care pathway issues. A clinical focus group consisting of three psychologists (including Gustaf Waxegård), one educational therapist and one occupational therapist, met at 40 occasions during 2009-2011 to analyse the care pathway from various perspectives. The meetings provided further data for analysis. Since the focus group members were employed in and continuously interacted with the care pathway, several hundred hours of participant observations were used in this study.

Internal and external experts on care pathways and ND, respectively, were consulted. Statistical and other descriptions of care processes were collected and treated as data. Routines, clinical guidelines, and policies were scrutinized locally as well as nationally. Reports on other on-going national or local similar projects were studied. Sit-ins with health care managers occurred continually throughout the project. Lastly, actions, such as managerial or team decisions, made by different care process stakeholders constituted data as well.

Data analysis

A classic grounded theory-approach (Glaser, 1978; 1998) was chosen as an analytic tool. Classic GT evaluates a theory according to whether it is possible to modify in the face of new contradictory data, has grab, fit, and relevance for the field under study. Sound theory is generated by an iterative process where recorded data are subject to constant comparison, coded into categories, elaborated in memo writing, and in an imperative to think conceptually, not descriptively. Data are not confined to a specific type but can be all sorts of observations; this statement is summarized under the well-known GT-dictum ”all is data”. GT studies can thus be dense with respect to the amount of data, and the data included are not always easy to exactly delineate. What matters is finding the relevant pattern(s) and naming them. In accordance with classic GT methodology, then, data were initially recorded in field notes. By constant comparison and coding of incidents, substantive codes emerged from memos that were written throughout the entire research process. Theoretical codes were tried against the data as interrelations between substantive codes, and eventually a theoretical model was generated explaining what was actually happening in the ND care pathway.

Theory development

Theory development can be tracked primarily in memos. Early conceptualizations were much concerned with fragmentation and sprawl. Sprawl was experienced as a main feature of ND as well as attitudes and competence with regard to ND in the care pathway. Structural changes of various sorts, and increased integration of health care to give patients a more ”seamless” experience of health care was a prominent way of addressing this issue in participants. In GT-terms this was properlining along the line of ”we should work together for the best of patients”. Observations collectively pointed to a host of factors obstructing this reasonable ambition. Gradually it became clearer that many of the participants explicitly or implicitly discussed how the complexity of ND

should be handled in the care pathway, and that a kind of game was played where several agendas competed.

In the end, two broad main agendas were conceptualized, the elaboration of care structures for ND and the downsizing ND structures. Both of these desires supposed a degree of control over own or other professionals' behavior in ND cases. Especially during the project implementation phase, the theory gradually changed from merely struggling with uncovering ND symptoms and needs in patients, to emphasizing control seeking behavior and recurrent trust-issues in relation to what we term "unpacking".

Ideally, GT pattern names are abstracted enough to be independent of time, place and people. The same pattern should be possible to identify at another point in time, in another setting and with different participants involved. Follow up-interviews in 2015 with additional professionals from two other Swedish regions were therefore carried out and provided confirmation of the usefulness of the theoretical concepts presented in this paper.

Kronoberg County Ethics Review Board approved the project in 2009 and deemed it not necessary to require regional ethics review according to Swedish research ethics legislation, since no patients were interviewed or approached.

Results

The main concerns for professionals when integrating ND care pathways for children and adolescents are to deal with the heterogeneity and complexity of the fast growing field of ND. The resolution of these concerns involves two core activity patterns: Unpacking control and Trust testing. These concepts are complementary interactive strategies to handle professional collaboration on the multifaceted and expansive ND arena. In this paper we focus on Trust testing, and start with a brief explanation of Unpacking control.

Unpacking control

The first core pattern was efforts to regulate ND complexity in the care pathway by controlling the professional means to represent it, what we call unpacking control.

Unpacking—the diagnosis and work up—is about choosing what aspects of ND patients' problems are conceptualized where, when, and by whom in the care pathway. Unpacking control is the attempt by professionals to influence how patients´ ND problems are defined, stemming from a concern for patients and their chances in life, from productivity demands and available care-issues, from a will to subsume ND into preferred ideological clinical and/or managerial paradigms, and, from a need to maintain workplace- or team integrity. To control a part of the unpacking process in the care pathway means to control the resources and approaches used when defining the patient's problems and strengths. A simple example is whether psychologists, managers, or physicians are in control of the amount, purpose, and implications of psychometric testing performed with patients. Unpacking control, when established, is typically used either to promote increased unpacking complexity or to downplay unpacking complexity, in the service of the aforementioned goals. To illustrate, unpacking routines can be simplified to achieve available health care, or elaborated to increase a valid understanding of the patient and the professional ability to help. The problematic results

are simultaneous attempts to up- and down-regulate care complexity in the ND care pathway.

In sum, unpacking control is critical in ND care pathway integration and used to up- and/or down-regulate unpacking capacity to solve the challenge of overwhelming ND-related complexity.

Level of unpacking complexity should not be confused with productivity. Up- as well as down-regulated capacity to unpack ND complexity in patients can be related to an increase as well as a decrease in productivity depending on contextual factors in the care pathway.

Trust testing

The second core pattern and topic of this article, trust testing, co-occurs with attempts by stakeholders in the ND care pathway to control unpacking to solve ND-complexity. Trust testing is defined as monitoring and acting on the perceived unpacking commitment of other stakeholders in the ND care pathway. Trust testing explores whether unpacking collaboration can occur without being exploited and if other stakeholders can be approached to solve own unpacking priorities. The main function is for professionals to decide on promoting local or collective control over unpacking in the care pathway. Trust testing thus regulates the opportunities for integrating the care pathway through collective action.

Trust testing is fuelled particularly by three contingencies related to the unpacking subcategory of squeezing ND-care, in other words, to maintain or increase patient turnover without an increase in resources. First, the default mode for an ND care pathway is that the population demand exceeds unpacking capacity. Second, to increase unpacking resources is impossible due to budget competition. Third, the political and managerial way of dealing with the situation is to act as if a short term solution to bottleneck problems without quality reduction is possible.

Under these premises, outcomes from stakeholder collaboration range from neutral to worse because of a temptation of all parts to transfer responsibility for unmet ND unpacking needs (in the served population) to other stakeholders. No or few solutions are available to restructure and integrate the care pathway without elements of "passing the buck" between care pathway units; such behavior results in weak incentives to integrate ND care. The rational thing to do in such a situation is not to play, or, alternatively, only pretend to play. But not pressing for integrating the ND care pathway is politically incorrect and not sanctioned, according to the third premise.

Stakeholders are thus obliged to play but develop a high sensitivity to being used or stuck with the buck. Those who naïvely play for care integration under the assumption that selfless cooperation will prevail are quickly let down when they learn the real rules of the game. Trust testing of others' unpacking intentions becomes the salient response to integrative efforts in the care pathway since the general "solution" to the unpacking conundrum is to either transfer workload to other stakeholders or to redefine unpacking tasks so as to fit better with locally available resources—implying but not admitting quality reduction.

The threshold for perceiving cooperative, integrative unpacking initiatives in the care pathway as altruistic in nature is high; rightly so, since self-interest to solve internal

problems of overload is a prime driving force for approaching care neighbors. Trust testing can have self-amplifying qualities when it leads to a partial concealment of true unpacking preferences by stakeholders. We saw a guessing game in the chain of care that necessitated further trust testing. The implicit question that participants in this case study posed was essentially: "Are they tuned in to our needs? If so, we will try and help them. Or, are they rather set on passing the buck?" The "buck" was, more often than not, increased unpacking responsibility for children and families and could result in clinic- or professional status degradation. Trust testing gauged the willingness to carry the agenda of another stakeholder if it yielded own unpacking control in return.

Dimensions of trust testing

We provide four dimensions that can be used to conceptualize trust testing of unpacking intentions.

First, trust testing can be naïve as opposed to sophisticated. The first naïve assumption is that trust can be built separate from the matter of unpacking. On the contrary, trust is created based on perceptions of responsible and competent unpacking. To fraternize is not enough to pass the trust test. The second naïve assumption is that the needs and wants of ND professionals and patients, in terms of unpacking, are the same at different care arenas; unpacking is a linear process that is suitable for industrial metaphors such as LEAN production. A sophisticated understanding is that unpacking frameworks differ between unpacking sites, care levels, and professions. For example, the preventive and developmental perspectives dominate the primary care well-child clinics, and a psychiatric and diagnostic perspective permeates the child psychiatric clinic. Failure to grasp the qualitative differences in patient relations established by different stakeholders amounts to being less trustworthy and a more naïve partner in care. Naïve assumptions, such as seeing other care units as mere forerunners or extensions of own patient work, are, however, tempting to act on since they make the care pathway jigsaw seem less complex than it is.

Second, trust testing ranges from dramatic to subtle. Dramatic trust testing increases the psychological distance between links in the care pathway and forces trust issues upwards in the hierarchy of the organization and outwards to citizens and media. It is exemplified by leaking information to journalists and other key agents. Dramatic trust testing is usually a response to perceived unethical or unacceptable unpacking behaviour, such as shortening waitlists by disregarding earlier unpacking efforts. High affect stand-offs between teams or employees and managers signal broken trust and the need for some kind of external action to make trust possible again. A tuned down dramatic variant is moral positioning, where moral superiority is claimed to promote the own unpacking stance. For example, clinicians on one team felt strongly that they were viewed as little disobedient children (i. e. not morally mature) by the management following disputes over best clinical practice. Subtle trust testing is to disclose only hints on one's own unpacking preferences and monitor the way it is treated by the other stakeholder. Subtle trust testing can lead to peculiar interactions and job meetings with the (accurate) impression that there is a lack of disclosure and that substantive issues are impossible to get at. Subtle trust testing leads to an evasive stance on ethical questions and on the related topic of how to prioritize among patient needs**.**

A third dimension is the hidden/public one. Trust testing can be dramatic but hidden from most people. It can be subtle but still taking place openly. Public trust

testing is risky when organizational levels of trust are low and the general impulse is not to trust new propositions. Hidden trust testing, where professionals or managers hide to confide in each other, conveys that other people cannot be trusted to take part in the decisions made. Hidden trust testing can generate a feeling of progress and saving time, but initiatives based on hidden trust testing were seldom successful in the current study. A peculiar example of a mix of open and hidden trust testing observed in this study was the "power point war", where fractions in the care pathway independently created PowerPoint presentations to capture their respective views on proper future unpacking. These were then made public to care pathway stakeholders.

The fourth dimension is the private-professional. Professional networks typically extend into the private life. The private arena is relatively free of professional constraints, making it attractive for a less censored trust testing process. Conflux of private and professional relations can complicate care pathway development and tends to remain a latent variable not amenable to open discussion. Awareness that private life constitutes a further arena for building alliances complicates establishment of professional trust. The semi-private sphere of social media can illustrate the breach between private and professional life: Private accounts in online social forums were used to join professional groups where proceedings in care pathways was debated. Some thoughtless commentaries in a professional group about the challenges ahead made by a newly appointed manager was immediately picked up by the future employees (and members of the same forum) and critically analysed outside of the forum, off-line, leading to eroded trust for the manager even before day one on the new job.

In sum, we found trust testing to pervade the ND care pathway and to extend into the private life of professionals. The function of trust testing is to explore whether other care pathway stakeholders are useful or use you in promoting a particular stance on ND unpacking. The outcome of trust testing regulates the chances of care pathway collaboration.

Discussion

This study suggests that a core pattern of trust testing arises when professionals are faced with improving ND service integration instead of working across boundaries. Trust testing is focused on controlling ND unpacking—the diagnosis and work up of ND.

Though professionals and managers endorse integration of services, co-existence is favored over coordination of care. We suggest that high demand for ND care, along with the inherent complexity of many ND cases, create a tendency in stakeholders to displace workload to other stakeholders, preferably without losing status and credibility in the care pathway. The key to displacement of workload is control over unpacking as it (unpacking) is the key to defining the patient´s further needs. Such an egoistic tendency coexists with a sincere wish as well as a politically defined job description to find the collective best ND care pathway solution. In a high demand-scarce resource context such as the one studied, professional, managerial, and clinic self-interest will become integral to issues of care coordination.

Trust testing is the key to avoid being the victim of workload displacement. Freeloading and self-interest has to be sorted out from altruistic collaboration. Trust testing can be used as an enhanced social dilemma perspective on the care pathway. A

social dilemma is a situation where rationality at the collective level is at odds with rationality at the individual or smaller group level (Dawes & Messick, 2000). In this study the pursuit of local concerns contributed to malfunction of the care pathway as a whole; one important aspect of trust testing is to explore whether social capital needed coordinate unpacking is at hand.

Negotiating and exploring trust, as in trust testing, indicates the presence of social dilemmas. Several game theoretical scenarios could be simulated in the ND care pathway using trust testing theory. The control game (Rothstein, 2001) occurred in several locations: a reference to professional or clinic distrust, based on experience or gossip, that a patient will get the care asked for after referral. Therefore, patient problem areas are highlighted to the degree of exaggeration and speculation. The receiving clinic in turn trivializes the claims, partly based on some experience with being played before. This creates incentives for the referring part to explain and perhaps exaggerate the next patient's needs even further. The control game has no evident equilibrium and lacks a solution. The entire context needs to change for it to end.

The assurance game (Tarrant, Stokes, & Colman, 2004) would correspond to stakeholder willingness to contribute to collective capacity of the ND care pathway without obvious immediate returns granted; they trust other stakeholders to show the same kind of altruism. We made several observations where one-sided unpacking strategies resulted in reduced trust and failed cooperation.

Dramatic trust testing has clear features of the game of chicken (de Heus, Hoogervorst, & Dijk, 2010): opponents racing head to head quickly raising the stakes, hoping that the other will defect before the crash.

So, decisions about collaboration in the care pathway are embedded in social dilemmas, explained by trust testing; trust is one of the most valuable resources to disarm social dilemmas. The complicated game matrix in this real-life setting probably reduces chances for finding solutions. Seen from this perspective, no one game dominates and the set-up is typically asymmetric (Bornstein, 2008) in that individuals play against groups, groups against groups and individuals against individuals, and they all play against the intricate nature of ND.

If the concepts of unpacking control and trust testing could be seen in light of a theoretical game, this may have explanatory value for care pathways dealing with complex problems while under pressure to find short-term solutions to long-term structural problems, such as excessive population demand on health care. The realization that the most rational thing to do for stakeholders under some circumstances is to defect, or not contribute to the collective good is critical. Without dilemma awareness, social traps can be hard to escape. Alternative explanations to stale situations, such as character flaws in employees or lack of moral in managers can be—and in this study, were—invoked and created downward spirals. If stakeholders develop dilemma awareness and are able to decode the situation at hand, mutual trust and vulnerability becomes a natural focus and known methods for escaping social traps (Kollock, 1998) can be applied for long-term success.

Limitations and strengths

Limitations of this study are that most of the empirical data were collected from one region in the South of Sweden and most of the rest of the data came from other parts of

Swedish ND care. This restriction challenges the generalizability to other contexts with different organisational and professional structures of ND care. However, the goal of grounded theory is to make the discovered concepts independent of time, place, and people. Our theory will have appeal to readers who recognize unpacking, trust testing, and its variations as something that resounds with their understanding of the ND discourse. Readers who do not recognize trust testing or unpacking as something pertinent for their ND understanding may not find the theory relevant in all its details. Yet, the large amount of data that has gone into the analysis has produced a useful hypothesis about the present Swedish ND landscape. The theory has been well received and recognized when being presented to various Swedish health care professionals.

Conclusions

First, integrating care pathways for complex bio-psycho-social conditions such as ND can benefit from a social dilemma framework to complement the traditional medical understanding of integrated care. A successful ND care pathway can be considered a public good (Van Dijk, De Cremer, Mulder, & Stouten, 2008) that will be realized if stakeholders decide to contribute to the collective best instead of maximizing self-interest. We conclude that ND complexity together with scarce resources and diverse stakeholder interests act as constraints on the ability to make selfless choices in terms of care cooperation. The letting go of unilateral control over unpacking issues then becomes contingent on exploring trustworthiness of care partners, in the absence of collectively accepted standards for ND unpacking.

Second, integrated health care pathways aim to reduce unwarranted variability in the care process, to improve quality and reduce costs. In this study, integrative attempts to reduce unpacking variability were resisted. We suggest that the field of ND has not reached a state of consensus as to what constitutes warranted as opposed to unwarranted variability in the care pathway. In an early article on integrated care pathways, Campbell et al., (1998) noted that it will be more difficult to develop integrated care pathways for complex or unusual conditions. ND certainly is complex and some ND diagnoses are unusual. Solving ND complexity demands that a large amount of flexibility is built into the care pathway. Such flexibility is under constant threat from stakeholder self-interest fed by the scarce resource-context. Also, an integrated care pathway with too many flexible exceptions is elongating itself from the defining idea of a care pathway, where there are well established decision trees for clearly defined situations. The messy heterogeneity of ND will always leave room for ambiguity and differing interpretations of what is at hand. We offer a preliminary conceptual framework for exploring and understanding dilemmas and challenges in the provision of care in complex areas of healthcare. A conclusion is that such care structures should pay as much attention to trust among professionals as to structures and flows.

References

Agle, B. R., Donaldson, T., Freeman, R. E., Jensen, M. C., Mitchell, R. K., & Wood, D. J. (2008). Dialogue: Toward superior stakeholder theory. *Business Ethics Quarterly, 18*(2), 153-190.

Ahgren, B. (2010). Mutualism and antagonism within organisations of integrated health care. *Journal of Health, Organisation and Management, 24(4)*, 396-411.

Barkley, R. A. (2002). Major life activity and health outcomes associated with attention-deficit/hyperactivity disorder. *Journal of Clinical Psychiatry, 63*(SUPPL. 12), 10-15.

Barkley, R. A., Fischer, M., Smallish, L., & Fletcher, K. (2002). The persistence of attention-deficit/hyperactivity disorder into young adulthood as a function of reporting source and definition of disorder. *Journal of Abnormal Psychology, 111*, 279-289. doi:10.1037/0021-843x.111.2.279

Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *British Journal of Psychiatry, 194*, 500-509. doi:10.1192/bjp.bp.108.059345

Blew, H., & Kenny, G. (2006). Attention deficit hyperactivity disorder: The current debate and neglected dimensions. *Journal of Child Health Care, 10*, 251-263. doi:10.1177/1367493506066485

Bornstein, G. (2008). A classification of games by player type. In A. Biel, D. Eek, T. Gärling, & M. Gustafsson (Eds.), *New issues and paradigms in research on social dilemmas* (pp. 27-42). New York, NY: Springer.

Brown, C. A. (2006). The application of complex adaptive systems theory to clinical practice in rehabilitation. *Disability and Rehabilitation, 28*, 587-593. doi:10.1080/00222930500219175

Burgess, I. C. (2002). Service innovations: Attention-deficit hyperactivity disorder - development of a multi-professional integrated care pathway. *Psychiatric Bulletin, 26*, 148-151. doi:10.1192/pb.26.4.148

Campbell, H., Hotchkiss, R., Bradshaw, N., & Porteous, M. (1998). Integrated care pathways. *British Medical Journal, 316*(7125), 133-137.

Cox, D. J. (2012). From interdisciplinary to integrated care of the child with autism: The essential role for a code of ethics. *Journal of Autism and Developmental Disorders, 42*, 2729-2738. doi:10.1007/s10803-012-1530-z

Daniels, A. M., Halladay, A. K., Shih, A., Elder, L. M., & Dawson, G. (2014). Approaches to enhancing the early detection of autism spectrum disorders: A systematic review of the literature. *Journal of the American Academy of Child and Adolescent Psychiatry, 53*, 141-152. doi:10.1016/j.jaac.2013.11.002

Dawes, R. M., & Messick, D. M. (2000). Social dilemmas. *International Journal of Psychology, 35*(2), 111-116.

de Heus, P., Hoogervorst, N., & Dijk, E. V. (2010). Framing prisoners and chickens: Valence effects in the prisoner's dilemma and the chicken game. *Journal of Experimental Social Psychology, 46*, 736-742. doi:10.1016/j.jesp.2010.04.013

Dodek, P., Cahill, N. E., & Heyland, D. K. (2010). The relationship between organizational culture and implementation of clinical practice guidelines: A narrative review. *Journal of Parenteral and Enteral Nutrition, 34*, 669-674. doi:10.1177/0148607110361905

Evans, J. M., & Baker, G. R. (2012). Shared mental models of integrated care: Aligning multiple stakeholder perspectives. *Journal of Health, Organisation and Management, 26*, 713-736. doi:10.1108/14777261211276989

Gillberg, C. (2010). The ESSENCE in child psychiatry: Early symptomatic syndromes eliciting neurodevelopmental clinical examinations. *Research in Developmental Disabilities, 31*, 1543-1551. doi:10.1016/j.ridd.2010.06.002

Gillberg, C., Cederlund, M., Lamberg, K., & Zeijlon, L. (2006). Brief report: "The autism epidemic". The registered prevalence of autism in a Swedish urban area. *Journal of Autism and Developmental Disorders, 36*, 429-435. doi:10.1007/s10803-006-0081-6

Gillberg, C., Gillberg, I. C., Rasmussen, P., Kadesjö, B., Söderström, H., Råstam, . . . , & Niklasson, L. (2004). Co-existing disorders in ADHD - Implications for diagnosis and intervention. *European Child and Adolescent Psychiatry, Supplement, 13*, I/80-I/92. doi:10.1007/s00787-004-1008-4

Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1998). *Doing grounded theory: Issues and discussions.* Mill Valley, CA: Sociology Press.

Guo, C., & Acar, M. (2005). Understanding collaboration among nonprofit organizations: Combining resource dependency, institutional, and network perspectives. *Nonprofit and Voluntary Sector Quarterly, 34*, 340-361. doi:10.1177/0899764005275411

Halperin, J. M., Bédard, A. C. V., & Curchack-Lichtin, J. T. (2012). Preventive interventions for ADHD: A neurodevelopmental perspective. *Neurotherapeutics, 9*, 531-541. doi:10.1007/s13311-012-0123-z

Kildea, S., Wright, J., & Davies, J. (2011). Making sense of ADHD in practice: A stakeholder review. *Clinical Child Psychology and Psychiatry, 16*, 599-619. doi:10.1177/1359104510390428

King, G., Cathers, T., King, S., & Rosenbaum, P. (2001). Major elements of parents' satisfaction and dissatisfaction with pediatric rehabilitation services. *Children's Health Care, 30*(2), 111-134.

Kirby, A., & Thomas, M. (2011). The whole child with developmental disorders. *British Journal of Hospital Medicine, 72*(3), 161-167.

Kollock, P. (1998). Social dilemmas: The anatomy of cooperation. *Annual Review of Sociology, 24*, 183-214. doi:10.1146/annurev.soc.24.1.183

Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J., . . . , & Lainhart, J. E. (2006). Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. *Journal of Autism and Developmental Disorders, 36*, 849-861. doi:10.1007/s10803-006-0123-0

McDaniel Jr, R. R., Lanham, H. J., & Anderson, R. A. (2009). Implications of complex adaptive systems theory for the design of research on health care organizations. *Health Care Management Review, 34*, 191-199. doi:10.1097/HMR.0b013e31819c8b38

Miller, A. R., Condin, C. J., McKellin, W. H., Shaw, N., Klassen, A. F., & Sheps, S. (2009). Continuity of care for children with complex chronic health conditions: Parents' perspectives. *BMC Health Serv Res, 9*, 242. doi:10.1186/1472-6963-9-242

Mur-Veeman, I., Hardy, B., Steenbergen, M., & Wistow, G. (2003). Development of integrated care in England and the Netherlands: Managing across public-private boundaries. *Health Policy, 65*, 227-241. doi:10.1016/s0168-8510(02)00215-4

Phillips, R., Freeman, R. E., & Wicks, A. C. (2003). What stakeholder theory is not. *Business Ethics Quarterly, 13*(4), 479-502+596+597+598.

Polanczyk, G., De Lima, M. S., Horta, B. L., Biederman, J., & Rohde, L. A. (2007). The worldwide prevalence of ADHD: A systematic review and metaregression analysis. *American Journal of Psychiatry, 164*, 942-948. doi:10.1176/appi.ajp.164.6.942

Posthuma, D., & Polderman, T. J. C. (2013). What have we learned from recent twin studies about the etiology of neurodevelopmental disorders? *Current Opinion in Neurology, 26*, 111-121. doi:10.1097/WCO.0b013e32835f19c3

Rommelse, N. N. J., Altink, M. E., Fliers, E. A., Martin, N. C., Buschgens, C. J. M., Hartman, C. A., . . . , & Oosterlaan, J. (2009). Comorbid problems in ADHD: Degree of association, shared endophenotypes, and formation of distinct subtypes. Implications for a future DSM. *Journal of Abnormal Child Psychology, 37*, 793-804. doi:10.1007/s10802-009-9312-6

Rommelse, N. N. J., Franke, B., Geurts, H. M., Hartman, C. A., & Buitelaar, J. K. (2010). Shared heritability of attention-deficit/hyperactivity disorder and autism spectrum disorder. *European Child and Adolescent Psychiatry, 19*, 281-295. doi:10.1007/s00787-010-0092-x

Ronald, A., Larsson, H., Anckarsäter, H., & Lichtenstein, P. (2014). Symptoms of autism and ADHD: A Swedish twin study examining their overlap. *Journal of Abnormal Psychology*. doi:10.1037/a0036088

Ronald, A., Simonoff, E., Kuntsi, J., Asherson, P., & Plomin, R. (2008). Evidence for overlapping genetic influences on autistic and ADHD behaviours in a community twin sample. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 49*, 535-542. doi:10.1111/j.1469-7610.2007.01857.x

Rothstein, B. (2001). The universal welfare state as a social dilemma. *Rationality and Society, 13*(2), 213-233.

Rutter, M. (2013a). Changing concepts and findings on autism. *Journal of Autism and Developmental Disorders, 43*(8), 1749-1757. doi:10.1007/s10803-012-1713-7

Rutter, M. (2013c). Developmental psychopathology: A paradigm shift or just a relabeling? *Dev Psychopathol, 25*, 1201-1213. doi:10.1017/S0954579413000564

Salmon, G., & Kirby, A. (2008). Schools: Central to providing comprehensive CAMH services in the future? *Child and Adolescent Mental Health, 13*, 107-114. doi:10.1111/j.1475-3588.2007.00468.x

Schein, E. H. (2006). From brainwashing to organizational therapy: A conceptual and empirical journey in search of 'systemic' health and a general model of change dynamics. A drama in five acts. *Organization Studies, 27*, 287-301. doi:10.1177/0170840606061831

Schmidt, S., & Petermann, F. (2009). Developmental psychopathology: Attention Deficit Hyperactivity Disorder (ADHD). *BMC Psychiatry, 9*, 58. doi:10.1186/1471-244X-9-58

Scott, C., & Hofmeyer, A. (2007). Networks and social capital: A relational approach to primary healthcare reform. *Health Research Policy and Systems, 5*. doi:10.1186/1478-4505-5-9

Singh, S. P., Paul, M., Ford, T., Kramer, T., Weaver, T., McLaren, S., . . . , & White, S. (2010). Process, outcome and experience of transition from child to adult mental healthcare: Multiperspective study. *British Journal of Psychiatry, 197*, 305-312. doi:10.1192/bjp.bp.109.075135

Tarrant, C., Stokes, T., & Colman, A. M. (2004). Models of the medical consultation: Opportunities and limitations of a game theory perspective. *Quality and Safety in Health Care, 13*, 461-466. doi:10.1136/qshc.2003.008417

Turgay, A., Goodman, D. W., Asherson, P., Lasser, R. A., Babcock, T. F., Pucci, M. L., & Barkley, R. (2012). Lifespan persistence of ADHD: The life transition model and its application. *Journal of Clinical Psychiatry, 73*, 192-201. doi:10.4088/JCP.10m06628

Van Dijk, E., De Cremer, D., Mulder, L. B., & Stouten, J. (2008). How do we react to feedback in social dilemmas? In A. Biel, D. Eek, T. Gärling, & M. Gustafsson (Eds.), *New issues and paradigms in research on social dilemmas* (pp. 43-56). New York, NY: Springer.

Van Raak, A., Paulus, A., & Mur-Veeman, I. (2005). Why do health and social care providers co-operate? *Health Policy, 74*, 13-23. doi:10.1016/j.healthpol.2004.12.006

Willcutt, E. G. (2012). The prevalence of DSM-IV Aattention-deficit/hyperactivity disorder: A meta-Analytic review. *Neurotherapeutics, 9*, 490-499. doi:10.1007/s13311-012-0135-8

Wiltsey Stirman, S., Kimberly, J., Cook, N., Calloway, A., Castro, F., & Charns, M. (2012). The sustainability of new programs and innovations: A review of the empirical literature and recommendations for future research. *Implementation Science, 7*. doi:10.1186/1748-5908-7-17

Wolraich, M. L., Wibbelsman, C. J., Brown, T. E., Evans, S. W., Gotlieb, E. M., Knight, J. R., . . . , & Wilens, T. (2005). Attention-deficit/hyperactivity disorder among adolescents: A review of the diagnosis, treatment, and clinical implications. *Pediatrics, 115*, 1734-1746. doi:10.1542/peds.2004-1959

Yoshida, Y., & Uchiyama, T. (2004). The clinical necessity for assessing attention deficit/hyperactivity disorder (AD/HD) symptoms in children with high-functioning pervasive developmental disorder (PDD). *European Child and Adolescent Psychiatry, 13*, 307-314. doi:10.1007/s00787-004-0391-1

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

Author´s contributions

Gustaf Waxegard carried out individual interviews, interviews with health care teams, and was in charge of focus group meetings. Gustaf Waxegard and Hans Thulesius jointly arranged the two-day dialogue conference and processed the data generated. Both authors were involved continuously in coding and memoing, albeit Gustaf Waxegard to a greater extent. Hans Thulesius has had a supervisory role based on his academic merits and his knowledge of and experience with the grounded theory method.

Acknowledgements

We wish to acknowledge the contributions to this study made by the Regions of Kronoberg, Gotland and Kalmar who generously provided access to care pathways for ND for several years. Both authors wrote this article on time financed by the Region´s Research and development unit. No other funding occurred. We also wish to thank all clinicians and managers participating in the interviews, focus groups and dialogue conference providing data for the study.