

Connecting Research Discovery with Care Delivery in Dementia: The Development of the
Indianapolis Discovery Network for Dementia

Malaz Boustani, MD, MPH (1,2,3); Amie Frame, MPH (1,2); Stephanie Munger, MPH (1,2);
Patrick Healey, MD (4); Jessie Westlund, RN (5); Martin Farlow, MD (6,7); Ann Hake, MD
(6,7); Mary Guerriero Austrom, PhD (6,8); Polly Shepard, PsyD (9); Corby Bubp, PhD (9); Jose
Azar, MD (3); Arif Nazir, MD (3); Nadia Adams, MHA (10); Noll Campbell, PharmD
(1,2,11,12); Paul Dexter, MD (2,3)

(1) Indiana University Center for Aging Research; (2) Regenstrief Institute, Inc.; (3) Department
of Medicine, Indiana University School of Medicine (IUSM); (4) St. Vincent Health Network;
(5) Community Health Network; (6) Indiana Alzheimer Disease Center, IUSM; (7) Department
of Neurology, IUSM; (8) Department of Psychiatry, IUSM; (9) The Memory Clinic of
Indianapolis; (10) Indiana University Health; (11) Department of Pharmacy Practice, Purdue
University College of Pharmacy; (12) Department of Pharmacy, Wishard Health Services

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Corresponding Author:

Malaz Boustani, MD, MPH

Regenstrief Institute, Inc.

410 West 10th Street, Suite 2000

Indianapolis, Indiana 46202

Phone: 317-423-5633

Fax: 317-423-5695

Email: mboustan@iupui.edu

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ABSTRACT:

BACKGROUND: The Institute of Medicine has recommended the need for an integrated, locally sensitive collaboration among the various members of the community, health care systems, and research organizations in order to improve dementia care and dementia research.

METHODS: Using the Complex Adaptive System theory and the Reflective Adaptive Process, we developed a social network called the Indianapolis Discovery Network for Dementia (IDND). IDND facilitates effective and sustainable interactions among a local and diverse group of dementia researchers, clinical providers, and community advocates interested in improving the care for dementia patients in Indianapolis, IN.

RESULTS: IDND was established in February 2006 and now includes more than 250 members from more than 30 local (central Indiana) organizations representing 20 disciplines. The network uses two types of communication to connect its members. The first is a 2-hour face-to-face bi-monthly meeting open to all members. The second is a web-based resource center (www.indydiscoverynetwork.org). To date, the network has accomplished: the development of a network website with an annual average of 12,711 hits per day; produced clinical tools such as the Healthy Aging Brain Care Monitor and the Anticholinergic Cognitive Burden Scale; translated and implemented the collaborative dementia care model into two local health care systems; created a web-based tracking software to support care coordination for patients with dementia called the Enhanced Medical Record for Aging Brain Care (eMR-ABC); members have received more than \$24 million in federal funding for dementia related research studies; and adopted a new group-based problem solving process called the “IDND-Consultancy Round”.

CONCLUSIONS: Building a local interdisciplinary “think-tank” network, focused on dementia, facilitates conducting collaborative research projects, educational initiatives, and quality

improvement efforts that meet the local research, clinical, and community needs relevant to dementia care.

INTRODUCTION:

Significant breakthroughs in basic research on the pathophysiology of dementing disorders and new innovative models of dementia care hold the promise of reducing the future burden of dementia (Alzheimer's Association Facts and Figures, 2012). However, the majority of dementia research is conducted in specialized research centers among patients who represent less than 1% of the patient population with dementia, with ethnic minority groups being largely underrepresented (Faison & Mintzer, AJGP 2004; Faison, IP 2007; Callahan and Boustani, JGIM 2008; Boustani et al, 2007; Callahan et al, JAGS 2008). Furthermore, the translation of innovative research discoveries into clinical practice typically takes an average of 17 years and the current research infrastructure fails to shorten this translational cycle (Westfall, 2007). The National Institutes of Health's (NIH) Roadmap and the Institute of Medicine (IOM) recognized the large gap in translating research innovations from discovery to delivery and recommended "Re-Engineering of the Clinical Research Enterprise." (NIH Roadmap 2007; Zerhouni, 2003; IOM, 2001)

The IOM and the NIH Roadmap recommended the use of complex adaptive system perspectives and information technology to build a localized and cohesive collaboration among the various members of the community, health care systems, and research organizations (NIH Roadmap 2007; Zerhouni, 2003; IOM, 2001). In response to the IOM and the NIH recommendations, the Regenstrief Institute, Inc., the Indiana University Center for Aging Research, and the Indiana Alzheimer Disease Center, have been building a network of health care providers, clinical researchers, and community advocates dedicated to enhancing the quality of life and care of individuals with dementia and the life and care of their informal caregivers, called the Indianapolis Discovery Network for Dementia (IDND). IDND has created an

environment that supports information and idea exchanges among its diverse and autonomous individuals allowing the network to accomplish its three-fold mission of facilitating the development of rapid, innovative health care solutions that meet local research, clinical, and community needs; (Campbell et al, CIA 2009) promoting a culture of discovery, cooperation, and team work among its diverse members; and (Boustani et al, Aging Health 2008) disseminating novel and effective dementia care knowledge within the various health care systems in Indianapolis. This article describes the theoretical framework, process, tools, and early successes of the IDND network, which we believe could help facilitate the building of similar dementia networks in other regions of the United States.

METHODS:

Theoretical Framework:

The Complex Adaptive System theory was selected to guide the structuring and development of a social network focused on reducing the societal burden of dementia by connecting local research activities with local dementia care delivery systems (Boustani, JClA 2010; IOM, 2001; Plsek, 1997; McDaniel, 2003; Lansing, 2003; Holden, 2005; Stroebel, 2005; Mathews, 2007; Zimmerman, 2001). A complex adaptive system is an open, dynamic and flexible network that is considered complex due to its composition of numerous interconnected, semi-autonomous, competing and collaborating members (Plsek, 1997; McDaniel, 2003; Lansing, 2003; Holden, 2005). This complex network is capable of learning from its prior experiences and is flexible to change the connecting pattern of its members to better fit with its environment and accomplish its various missions and tasks (Plsek, 1997; McDaniel, 2003; Lansing, 2003; Holden, 2005; Stroebel 2005; Mathews 2007). Furthermore, complex adaptive

systems are characterized by emergent behaviors as opposed to predetermined ones and self-organized controls instead of hierarchical controls (Plsek, 1997; McDaniel, 2003; Lansing, 2003; Holden, 2005; Stroebel, 2005; Mathews, 2007). Health care delivery organizations, universities, and internet-based social networks are considered examples of complex adaptive systems (Zimmerman, 2001; Boustani, JGIM 2007; Boustani, JCIA 2010; IOM, 2001; Plsek, 1997; McDaniel, 2003; Lansing, 2003; Holden, 2005; Stroebel 2005; Mathews, 2007).

To organize, facilitate, and sustain effective interactions among the network's autonomous members we applied the Nine Emerging and Connected Organizational and Leadership Principles of the complex adaptive system theory (Zimmerman, Lindberg, Plsek, 1998).

These guiding principles are:

- View the social network as an unpredictable and complex.
- Work on building an acceptable vision for the network with minimum specifications rather than having a detailed and rigid operational manual.
- Direct and guide the network dynamics and interactions by balancing data and intuition, planning and acting, safety and risk.
- Encourage and promote a balance of information flow, connection channels, diversity, power differential, and tension among network members instead of controlling information exchange, forcing agreement, and dealing separately with contentious groups. Avoid working systematically down all the layers of the hierarchy in sequence and seeking comfort.
- Uncover and work with paradox and tension rather than shying away from them.

- Go for multiple actions at the fringes, let direction arise rather than micro-planning every step and searching for the highest level of certainty.
- Listen to the informal relationships, gossip, rumor, and hallway conversations that contribute significantly to the individuals' perceptions about their surrounding environment and their subsequent actions.
- Allow complex sub-networks to emerge out of the links among simple networks that work well and are capable of operating independently.
- Build a community of members who collaborate, create, learn and compete; it is not one or the other.

Building on these principles, we chose to incorporate the Reflective Adaptive Process (RAP) as a practical method focused on using Complex Adaptive System principles to introduce acceptable and effective change (Stroebe, 2005; McDaniel, 2003; Boustani et al., JCI 2010). RAP facilitates the development of strategies not prescribed protocols and change built on explicit opportunities for learning, reflection, and adaptation.

The five guiding principles of RAP include:

- Vision, mission, and shared values are fundamental in guiding ongoing change processes in a complex adaptive system;
- Creating time and space for learning and reflection is necessary for a complex adaptive system to adapt to and plan for change;
- Tension and discomfort are essential and normal during complex adaptive systems changes;
- Improvement teams should include a variety of the system's agents with different perspectives of the system and its environment; and

- System change requires supportive leadership that is actively involved in the change process, ensuring full participation from all members and protecting time for reflection (Stroebe, 2005) (see Table 1).

Development Process:

The IDND development process began with the formation of a cross-functional operational team consisting of the Network Director and Coordinator and representatives from both academic and non-academic memory care practices, a dementia educator, and a research representative from the pharmaceutical industry. Our operational team used iterative cycles to identify priority improvement opportunities, discuss potential solutions, pilot several changes, and reflect on the impact of changes.

Membership:

The IDND Network Director and Coordinator explored existing relationships with local professionals to identify potential members who shared the goals of the network and practiced within Indianapolis metropolitan area. Membership was open to various disciplines such as physicians, nurses, psychologists, social workers, health care administrators, pharmacists, and public health officers, including representatives of the major health care systems in the metropolitan area: Wishard Health Care System, Indiana University Health (IU Health), St. Vincent Health, Community Health Network, and Saint Francis Health Care. In addition, the Alzheimer's Association of Greater Indiana and the Indianapolis Minority Health Coalition participate as representatives of local advocacy organizations. Representatives from other local pharmaceutical companies or for-profit organizations who shared an interest in the goals and objectives of the Network were not excluded from membership.

The Consultancy Model:

The **IDND consultancy round** offers a structured time and space for the generation and sharing of innovative ideas, potential solutions, and member-to-member shared perspectives and support. This group-based problem solving process is a modified version of a peer-to-peer advisory activity that was developed by the John A Hartford Foundation to support interaction between the foundation's interdisciplinary grantees and scholars. (www.jhartfound.org) The IDND consultancy round part of the bimonthly meeting, is limited to 60 minutes, and has the following specifications: 1) Prior to each meeting, an IDND member selects a clinical, educational, or research challenge for which he /she would like to seek feedback from other members; 2) The presenter has up to 15 minutes to present his/her selected challenge using a typical oral presentation with or without the use of PowerPoint or other media; 3) All meeting attendants have up to 5 minutes to ask clarifying questions related to the presented challenge; 4) Each IDND member has up to 2 minutes to provide solutions or feedbacks to the presenter; no IDND member can criticize or respond to any of the feedback or solutions presented by other IDND members; 5) The presenter will have up to 5 minutes to summarize the feedback received; he/she cannot respond to suggestions from the IDND members; 6) Following the feedback summary, the group will have an open discussion regarding the themes generated from the consultancy round. The IDND Coordinator records all of the solutions and shares them with the presenter and other IDND members upon request.

In each IDND meeting, there is a 30-minute time period, before and after the consultancy round, designed to enhance social interaction and networking among members. During this time, the Network Director introduces new members and briefly celebrates IDND members' recent accomplishments. The Director is also responsible for monitoring the process

of the IDND consultancy round, gathering information generated during the meetings, and encouraging participation and self-reflection.

RESULTS:

Today, the IDND includes more than 250 members representing 20 disciplines and more than 30 local organizations (See Table 2). Since its inception in February 2006, IDND has conducted over 30 consultancy rounds that covered educational, research, and clinical problems presented by 20 different members. It incorporates both leadership and “front-line” representation from the disciplines of clinical medicine, economics, research, biostatistics, information technology and marketing. IDND has members from eight memory care practices representing five of the different Indiana health care systems. The model of dementia care within each memory care practice varies with some clinics using a dedicated dementia care nurse specialist while others use both a nurse and social worker with expertise in dementia care. (See Figure 1). Two of these memory care practices have successfully translated the collaborative dementia care model into self-sustained clinical services (Boustani et al, *Aging and Mental Health* 2011)

IDND has also facilitated the recruitment and execution of more than 10 research projects awarded more than \$24 million dollars in funding and recruited more than 2500 participants (See Table 3). Furthermore, IDND-supported projects and educational opportunities have resulted in the development of multiple clinical tools including the Healthy Aging Brain Center Monitor, e-CHAMP delirium protocols, RAPID-PC assessment cards, and the Anticholinergic Cognitive Burden list available for professionals online through the IDND website’s resource center. Two of the most successful products of IDND’s collaborative efforts include the HABC Monitor and the Anticholinergic Cognitive Burden list (ACB).

In hypertension care, the "blood pressure cuff" is one tool that is used for screening, diagnosis, and monitoring. Based on the "blood pressure cuff" concept, the HABC monitor was developed to function similarly in dementia care: one instrument capable of achieving all three processes. The development of the HABC monitor was based on data collection from our previous studies and its face validity tested using the feedback of an interdisciplinary team of 22 representatives from three disciplines; clinical care, clinical research, and psychometrics, who were involved in dementia care and research. There are two versions of the monitor, the HABC Caregiver version and HABC Self-Report version, both of which are actively being used in several of our local affiliated memory care practices.

Literature strongly supports the increased risk of acute cognitive impairment and possibly chronic cognitive impairment in older adults using anticholinergic medications. While physicians are aware of the side effects of drugs within the anticholinergic category, many may not recognize the anticholinergic properties of new drugs to the market or those with unrecognized anticholinergic properties. To assist with the recognition of these medications, our interdisciplinary team developed the Anticholinergic Cognitive Burden (ACB) list as a practical tool that identifies the severity of anticholinergic effects from both prescription and over-the-counter medications on cognition.

One of the largest and long-term development projects of IDND is the construction of an enhanced medical record for aging brain care (eMR-ABC), a web-based medical record system that meets the needs of dementia research and care. As a first step in building eMR-ABC, IDND consulted with the leadership of IUCAR and the Regenstrief Institute, Inc and organized two meetings with the entire IDND clinical providers in an effort to understand the providers' perspectives about potential barriers for eMR-ABC. The meetings with the clinical providers

identified the following critical elements necessary to build an efficient and successful eMR-ABC:

- Clinicians and researchers need to identify potential patients with dementia using criteria that represents a community standard;
- Clinicians and researchers need to reach consensus on the data elements relevant to both dementia care and research that should be collected, stored, and tracked;
- eMR-ABC must store and safeguard data in a consistent format using accepted standards;
- eMR-ABC must be able to transmit dementia-related data in a standardized format;
- eMR-ABC must incorporate tools that are feasible and familiar to all personnel involved in collecting the data; and
- eMR-ABC must be governed through an interdisciplinary operations team.

IDND has successfully completed a pilot test of its eMR-ABC in one health care system and has received additional funding to upgrade the current program and continue further testing on a larger scale to assure its capability of capturing reliable data related to dementia care and outcomes; to assure its ability in managing, summarizing, and presenting captured data to various eligible researchers and clinicians; and assure its ability in facilitating dementia research activities by identifying potential subjects for various studies and tracking their health outcomes.

Over the past 12 months, the IDND website has been redesigned to improve its user-interface, offer more resources, and create an additional environment for networking amongst members. The website serves as an open source repository for network members and the public by providing an array of information including past dinner presentations, links to external resources for both the patient and the caregiver, IDND products such as the HABC Monitor and

the ACB Scale, calendar of events for both IDND and community and clinic collaborators, and interesting articles and journal publications related to dementia research and care. The website also offers the opportunity to its members to list information on the website about the clinics, facilities, and organizations they represent. The website receives an average of 12,000 hits and 600 visits per day. Although the IDND network consists primarily of local members, the website allows wide access to IDND.

Additionally, IDND's continued expansion and the growing needs of dementia research prompted the development of two core groups within IDND: the IDND Governing Body and the Patient Advisory Board. Both groups were established to assist the Operational Body, which includes the Network Director, Associate Director, and the Assistant Network Director, in the decision making process of the network. The IDND Governing Body consists of 15 members divided into three subgroups: Memory Care Practice (6 positions), Long Term Care (1 position), and Elected members (8 positions) comprised of experts in information technology, legal, finance, education and public relations. The Governing Body also contains 5 subcommittees: Education, Clinical Practice and Implementation Guidelines, Research and Implementation, Governance, and Finance and Accountability; each subcommittee is directed by a Chair and Vice Chair positions elected by the Governing Body members. Members of the first Governing Body were selected and voted for by the core members of IDND who were instrumental in its early development. To facilitate its function, the Operational team also created Guidelines for the Governing Body which includes position and term definitions, voting protocols, its role in assisting the Network in maintaining its value and meeting its mission and goals. The Governing Body meets quarterly throughout the year and is also directed by two, nominated Chair and Vice Chair positions.

The Patient Advisory Board was developed to add a unique perspective to the consultancy round as well as to respond to new requests by federal funders for the addition of patient/caregiver input on the design and implementation of new dementia research that may influence their outcomes. The IDND Patient Advisory Board consists of 8 active members of patients and their caregivers. As active members, they are asked to attend the regular IDND consultancy dinners.

As IDND continues to expand, one step in its growth is to help IDND's member memory practices form a practice based research network (PBRN). PBRNs offer advantages to both research and quality improvement initiatives, with their ability to move scientific advances into daily practice quickly, and their ability to incorporate practice-relevant topics into the research agenda (Gilbert – Creation of dental PBRN). Most recently, IDND was recognized by the U.S. Department of Health and Human Services' Agency for Healthcare Research and Quality as an Affiliate Primary Care Practice-Based Research Network.

DISCUSSION:

Within the last six years, IDND has been a competitive force in the development and delivery of new and innovative dementia care research. In turn, research founded and supported through IDND has yielded multiple journal publications and invitations to present work at seminars and conferences throughout the nation. Despite early successes, IDND has not been paralyzed by its early achievements, but preserving its momentum, and evolving to meet the changing needs of the community it serves.

As IDND moves forward in creating and achieving its new goals, it has much to learn about the history and successes of other community and practice based research networks.

Although the infrastructures of CROs and PBRNs vary widely, they do share some common elements: mission statement, a director, support staff, communication processes, and community advisory board (Green et al, 2005; AHRQ, 2004). As IDND has continued to grow in number and diversity, it has been successful in its rigorous adherence to its original mission and goals while maintaining complexity. Similarly to other community research networks, IDND's mission and goals are narrow and specific. IDND's primary focus is dementia research and dissemination, however, the research supported by IDND has been conceptualized, executed, and led largely by the IDND Network Director; collaborative efforts among the IDND group have been limited to recruitment and dissemination. This is not a result of lack of support from the IDND leadership in encouraging IDND members to explore their own research interests, but, perhaps the lack of guidance. Within the last year, the Network responded by establishing a Governing Body and Patient Advisory Board to assist members at any point along the research timeline (i.e. grant proposal, study design, recruitment, data collection and analysis, and implementation).

The IDND Governing Body and Patient Advisory Board were developed to guide the IDND members in their research development and implementation. Unlike other research networks with elaborate leadership panels and established by-laws, the Governing Body and Advisory Board have limited decision making power. Guidelines were developed but only to document the developmental process of the board and to define the roles of each for the Network members. It is at the discretion of the investigator and research study team to respond to advice given. Although not a requirement among all community networks, patient representation within IDND ensures patient input on the decision making process and project development. Unlike other patient advisory boards which are restricted to patients only or patients with specific forms

of dementia or disease, IDND's definition of "patient" includes the informal caregiver allowing IDND to develop research that addresses the needs of both. Although the functions of the Governing Body and Patient Advisory Board for IDND are continuing to be defined, even in their juvenile state, both groups have already made significant contributions to IDND. Changes to the Network's infrastructure, mission, goals and values are unanimously determined by the IDND leadership and core founders.

For most networks, funding is a constant obstacle, which can limit the degree of size, outreach, and direction of the network's growth (Pulcini et al, 2008). For IDND, the primary financial source is federally funded research of IDND members. IDND can benefit from the establishment of financial relationships with outside entities that share the network's initiatives. Other research networks, such as the Alzheimer's Association of Indianapolis, have sponsors and additional financial partners which allows for flexibility, increased involvement, and a larger societal impact. Although IDND has the interest and representation of the major health care systems in the Indianapolis area, exploration of additional funding is necessary in order to translate IDND into a national model for the building of regional and national dementia networks.

Communication tools vary among networks including email listservs, newsletters, website, and face-to-face meetings (Green et al, 2005). For IDND, information exchange has been unidirectional, primarily through email, newsletters, and the IDND website. With the exception of the regular dinner meetings, most IDND members do not have other opportunities to communicate with the IDND Administration and other network members. The use of message boards and e-Newsletters have been instrumental for other research networks in increasing

information exchange among its members, gaining interest of new parties, and expansion of research.

Although IDND has had many successes within its first years of operation, further development is needed in the financial and communication facets of the network as well as increased research proposition and involvement from other members to ensure longevity and lifelong societal impact. Improvements in these areas will result in opportunities for regional and national recognition and the translation of the IDND model into the building of other dementia discovery networks. These regional networks would be the ideal testing ground for new ideas and technologies for primary, secondary and tertiary dementia prevention creating more opportunity for collaborative research projects, quality improvement, and global impact.

Table 1: Applying the Reflective Adaptive Process to the Development of IDND

Principle	Local application
Shared values are fundamental in guiding ongoing change processes in a CAS.	The interdisciplinary network would (a) facilitate conducting dementia quality improvement and clinical research activities that meet the local research, clinical, and community needs; (b) promote a culture of discovery, cooperation, and team work among its diverse members; and (c) disseminate knowledge and innovations in dementia care.
Creating time and space for learning and reflection to adapt and plan change.	Bimonthly face-to-face meetings and web-based resource center
Tension and discomfort are normal in introducing a change within a CAS.	The IDND consultancy round provides a structure to facilitate discussion, feedback, and review.
Improvement team should include a variety of system's agents with different perspectives of the system and its environment.	IDND membership is comprised of an interdisciplinary matrix of people with the relevant roles, expertise, skills, and perspectives. It includes geriatricians, neurologists, psychiatrists, psychologists, nurses, social workers, public

	health officers, health administrators, clinical researchers, and medical informaticians.
System change requires supportive and active leadership	IDND has a leadership representative the five health care systems in Indianapolis, the Alzheimer associations, and Indiana Minority Health Coalition.

Table 2: Characteristics of IDND Members

<u>Members & Practices:</u>	
Total Number of Members	250
Total Number of Practices, Clinics	8
Total Number of Patients Served	5000
<u>Profession:</u>	
Physicians	66
Nurse Practitioners	15
Physician Assistants	2
Other Clinicians	100
Other Members	67
<u>Physician Specialties:</u>	
General Internal Medicine	30
Other: Neurology, Psychiatry, Geriatrics	40

Table 3: Funding for IDND Supported Projects

PROJECT	TOTAL AWARD AMOUNT
ADMIT	\$2,706,383
PROSPECT	\$8,422,410
PRISM	\$872,263
FOREST PHARMACEUTICALS	\$222,000
NOVARTIS	\$226,200
ROYBAL – HABC MONITOR	\$61,730
IN-PEACE	\$154,000
CHIP	\$2,846,877
IADC	\$8,817,465
IPRISP	\$456,018
TOTAL	\$24,785,346

Figure 1: IDND-Practice Based Research Network

