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Communication with Individuals with Intellectual Disabilities and Psychiatric Disabilities: A Summary of the Literature

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Introduction

Communication is an integral part of the human experience in which most individuals engage daily. The American Speech-Language Hearing Association (ASHA) defines communication as, "any act by which one person gives or receives from another person information about that person's needs, desires, perceptions, knowledge, or affective states." The ASHA guidelines further specify that communication can be, "intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or nonlinguistic forms, and may occur through spoken or other modes" (ASHA, 1992).

Two groups that may experience difficulties with communication are (a) those with cognitive, developmental, or intellectual disabilities (ID), for example those with autism, "mental retardation," or cerebral palsy, and (b) those with psychiatric disabilities (PD), for example those with depression, schizophrenia, or bipolar disorder. These populations have a wide range of cognitive, expressive and receptive capacities.

Governmental agencies serve individuals in both of these groups and must consequently communicate with these individuals at multiple points, from interviews with claims representatives to written notices sent to applicants and beneficiaries about highly complex material. Thus information in the social scientific, survey research-based, cognitive testing-based and other relevant literatures about how to communicate effectively with these individuals can be useful at a practical level to governmental service providers.

Given the nature of governmental contact with individuals with ID/PD, particular interest falls upon formal written communication, but other modes of communicating factual information (e.g., telephone, in-person)

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are also within the scope of this literature review. We focus on whether there is research regarding the ability to test comprehension of written materials by individuals with ID/PD that might inform governmental efforts. Consequently, the scope of the following review includes a wide sweep of mechanisms of communication with individuals with ID/PD with the express intent of offering further insights for those in government who interact with such individuals.

Methodology

In order to perform a systematic review of the diverse and multi-disciplinary literature, we employed a snowball technique, searching references of references and using citation-tracking databases. We identified seminal sources in each meta-narrative by asking what were cited as key original and scholarly contributions by other researchers in the same tradition. From this collection of material, we read the primary sources and used narratives to summarize their key methods and findings. With these sources, we extracted the concepts, theories, and preferred methods that formed the criteria for rigor in each meta-narrative, and used these to guide our appraisal of empirical studies. We gave greater weight to studies that had been flagged as "high quality" by other scholars in a tradition, but because the literature includes a wide range of different paradigms, perspectives, and study designs, we did not use a formal qualitative scoring system. Moreover, given the growth of new technologies in communication, slightly greater weight was given to more recent publications in order to encourage a slight bias towards approaches that may (or may not) prove to be cutting edge for government agencies.

Intellectual Disability

Intellectual disability (ID) refers to a wide range of clinical conditions with diverse etiologies, involving a wide range of neural deficits and mental abilities. In general, ID is a collection of conditions of incomplete or arrested development of the brain and associated structures. Many of these conditions affect communication.

We examine the current literature on communication with adults with ID. We evaluate what is known regarding the receptive and expressive communicative capacities of these individuals. With an aim to determine how the literature may inform a set of evidence-based best practices, we suggest many ways in which communication could be improved (a) when attempting to communicate a concept to an individual with ID, and (b) when attempting to elicit and understand an idea being communicated by an individual with ID.

Psychiatric Disability

Psychiatric disability (PD) refers to a wide range of clinical conditions with diverse etiologies, involving a large variety of functional deficits and mental abilities. As in ID, many of these situations affect communication. Serious mental illnesses, such as schizophrenia, schizoaffective disorder, and bipolar disorder, provoke consequential functional debilities and are some of the leading causes of disability.

We examine the current literature on communication with individuals with PD. We will attempt to evaluate what is known regarding the communicative strategies with an aim to determine how the literature may inform a set of evidence-based best practices regarding how to most effectively and efficiently communicate with individuals with PD.

Written- and Internet-based Psychoeducation

For individuals with PD, a uniform theme is that written communication is often efficacious as a medium of information exchange. Despite the receptive impairment of cognitive defects, written material often transmits significant amounts of data. Equally, and especially when augmented with face-to-face support, therapeutic value attends written communication.

We find that there is emerging, if not rock-solid, evidence that multi-media communication promises valuable results. Interactive and self-guided media have proven effective, especially in psycho-education. Online efforts, for example, have embraced support groups and blogs, Skype and webcams, interactive, self-guided interactions, as well as SMS and handheld device apps. However, few randomized controlled trials support solid evidence-based conclusions. Confounders frequently involve co-morbidities like ID and variation in support staff for the individual consumer with PD.

Design of Written Communicative Materials for Psychoeducation, Including Users in Development

The data supports involving users (i.e., individuals with PD) in design of materials and services, with researchers arguing that such participation is crucial and consequently results in better outcomes.

Some have argued that at least four levels of collaboration should occur: (a) in the interaction between service users and in the form of self-help; (b) in the interaction between individual users and professionals working with them; (c) in the management of local services; and (d) in the planning of overall services.

Interventions to Manage Care / Improve Medication Adherence among Adults with Serious Psychiatric Disabilities

The communicative strategies to manage or improve self-care involve cognitive reinforcement (for example, emphasizing memory-based reminders for taking medications) or structural access (for example, financial or physical access to clinics or pharmacies). Simplicity and concreteness were qualities of communicative solutions frequently recommended in the literature.

Involvement of the Family in Education and Care

In the lived experience of identification, treatment and support of individuals with PD, no support surpasses the intimacy of biological and socially validated family. However, families often feel marginalized, ignored or even excluded from information-gathering and decision-making.

Training of professionals in principles of respect, autonomy and legal/regulatory/guideline-based boundaries is crucial to successfully navigating the benefits and challenges of family involvement. A number of models, if not formally evaluated as best practices, exist for consideration/adaptation, including a consultative model.

Ability of Psychiatric Patients to Communicate and Participate in Shared Decision Making (SDM)

Individuals with PD frequently have challenges with communication, including poor insight and deficiencies in pragmatic language use. When afforded the opportunity for SDM, patient outcomes are often better. Service providers thus have an increased responsibility to overcome communicative barriers.

In sum, people with PD want to be involved. Generally they welcome information and the ability to participate in decision-making. For advanced directives and SDM, two complex cognitive activities, there is benefit to having the patient involved. Consequently, similar activities for governmental agencies might be amenable to some of the communication strategies above.

Strategies to Enhance Satisfaction in Healthcare Settings and in Higher Education

The literature shows that concern for stigmatization is seminal amongst individuals with PD interacting with larger social institutions such as health care and higher education.

Especially for individuals with PD, intra-professional communication is also critical. Emphasizing autonomy and self-determination promotes a structure of mutual trust, collaboration and attention to the expressive nature of the individual with PD. It equally mitigates unintentionally coercive processes, while stressing recovery and creativity.

We summarize a list of best-practices from the literature (a) when attempting to communicate a concept to an individual with PD, (b) when attempting to elicit and understand an idea being communicated by an individual with PD, and (c) when fashioning in-the-field policies relating to those with PD.

Conclusion

Core guidance emerges in this review for those communicating with individuals with ID and PD:

- Respect for the autonomy of the individuals being served (client).
- Sensitivity to the stigmatizing power of labeled disabilities.
- Active involvement of clients in the design of programmatics.
- Individualization of communication strategies to meet the specific needs of the particular client.
- Multidisciplinary collaboration, cooperation and communication in order to facilitate communication with the client.
- Family and/or community collaboration, within the boundaries of confidentiality requirements.
- Ongoing exploration of both newfangled and traditional media of communication.

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