

Strategic Plan: Creating an Autism Registry in Vietnam

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Abstract

As a neurological disorder diagnosed during childhood that impairs social functioning, people with autism require developmentally focused care so that the highest possible quality of life can be achieved (Elsabbagh, Divan, Koh ... & Kim, 2012). In developing countries with fewer mental health resources, it is especially important to have a system of tracking children who are diagnosed with autism in order to ensure proper treatment (Maguire, 2013). Therefore, through an organization called MEDRIX, it is essential to develop a strategic plan that helps to create an autism registry for children in Vietnam.

Keywords: Vietnam, autism, MEDRIX

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Section 1: Problem Identification

Currently, there is no method of recording the number of children with autism in Vietnam, and because of this, these children are not being effectively treated. Therefore, the International Non-Government Organization/Non-Profit Organization (INGO/NPO), MEDRIX, plans to create a registry in Vietnam for children with autism. Strategically, this plan fulfills a need by creating a registry to track Vietnamese children with autism. Operationally, it is imperative to explore both the cost of such a program and the type current health care registries that exist in order to observe a working model.

When considering the significance of the problem, it is important to deliberate on the cultural factors that influence diagnosing autism in Asia. For example, “In South Korea, the stigma of autism is so intense that many families of children with developmental delays will intentionally avoid diagnosis of ASD [autism spectrum disorders]” (Maguire, 2013). A lack of resources, such as a psychiatrist to layperson ratio of 1:100,000 in South East Asia, is another issue that contributes to scarce autism data specifically in South East Asian countries (Maguire, 2013). The National Institute of Health published a recent compilation of data, stating, “Only one estimate of AD [autism disorder] was available from South East Asia. The study conducted in Indonesia estimated the rate of AD to be 11.7/10,000” (Elsabbagh et al., 2012). However, this data is decades old, stemming from a study in 1992. By knowing the incidence and prevalence of autism in Vietnam via an autism registry, clinicians will be able to strategize more current autism research in order to improve developmental outcomes for these children. Operationally, it is important to consider the kind of staffing that is required to maintain this type of registry.

Philosophically, a developed country like the United States is responsible for providing resources to help improve mental health outcomes for individuals in developing countries, such as Vietnam. This will allow the Vietnamese health care community to take ownership in addressing a stigmatized mental health problem. On the other hand, operationally, it is vital to consider whether or not the Vietnamese government will approve of this type of resource.

Section 2: Mission Statement of the Organization

MEDRIX (Medical, Education, Development Resources, International eXchange) mission is saving lives and improving the quality of life in Vietnam by providing medical resources, international health education, child heart surgeries and safe water development (MEDRIX, 2014).

Section 3: Statement of Strategic Planning and Goals

The goal of this strategic plan is to explore and determine if a health registry and/or multiple health registries have been established in Vietnam to recommend for the INGO/NPO, MEDRIX, in their venture in establishing a pediatric autism registry. This registry is intended to document and follow clients diagnosed on the autism spectrum within the country. It is clear that health care related registries are present in various South East Asian and surrounding countries. For example, Malaysia, India, and Pakistan each have a registry that outlines variables relating to cost, use, and availability of kidney dialysis for patients with chronic kidney disease (Jha, 2009). Specifically, MEDRIX works to provide resources and health education to improve the lives and health status of children in Vietnam. By creating a registry to track children with autism, MEDRIX is working to link and supply care to these children and their families (MEDRIX, 2014).

Exploring previous projects in the establishment of registries in Vietnam will ultimately discern the timeframe and resources required, as well as financial and legal stipulations behind previous registries, to create a functional autism related registry for pediatric clients within the country. Upon the determination of an established registry, it will be possible to use it as a model, specifically focusing on the timeframe and resources needed, for a successful autism record. Furthermore, it will be important and helpful to explore the financial aspects as well as legality, explicitly concerning governmental influence, concerning a registry in Vietnam. Using previous registry experiences as guide, it will be possible to determine an estimated cost and necessary resources.

Section 4: Proforma

SWOT Analysis

Strengths internal to the organization/initiative. One of the more difficult aspects of bringing health care services into a foreign country includes working with the government and regulatory agencies. MEDRIX has been building trust and respect with the Vietnamese government for just over a decade, and this is a strength that helps lay the foundation for medical care to be made available to the Vietnamese people. As an American organization, MEDRIX already has more intimate access into the country in terms of health care influence, which is the starting point that will potentiate plans for a nation-wide autism registry (MEDRIX, 2014).

Another strength of MEDRIX is that it has been building trust with the local people in Vietnam since 2002. Without a sense of trust, the registry would be useless, as no one would be willing to enroll their child in the program, for fear of being ostracized from their own community. Having access to diverse resources, such as foreign as well as native health care

providers and medical professionals, will allow for greater quality of care, as the care provided will be culturally competent and economically realistic (MEDRIX, 2014).

Weaknesses internal to the organization/initiative. Weaknesses need to be recognized within the organization before resolutions can be formed and actions taken. One of these weaknesses includes the difference in culture and approach to healthcare, when comparing those who founded and operate MEDRIX and those who will be receiving medical care from this organization. Cultural barriers are a concern when considering any plan that involves penetrating international borders.

Limited staffing with MEDRIX is another weakness needing recognition, as this organization relies on volunteers for health care endeavors in Vietnam. In order for this health registry to move forward, MEDRIX may need to consider recruitment strategies for volunteers as well as other organizations (MEDRIX, 2014).

Opportunities external to the organization/initiative. MEDRIX has the ability to help a previously unreached population. Vietnam has a wide spectrum of living arrangements, with families living in cities and others living in remote villages. By creating this registry, MEDRIX will be on the front line of mental health and autism registries in this region. Creating this registry will not only help to ensure continuity of care for these patients, but will also bolster the public image of MEDRIX amongst South East Asian INGO/NPOs (MEDRIX, 2014).

In creating this registry, MEDRIX will have the ability to partner with other nonprofits in the area. By combining information from multiple registries in one geographical area, MEDRIX and its partners will be able to gather important data that could be used for research and strategic planning for other health care needs.

Threats external to the organization/initiative. It is not uncommon in Asian cultures to see diseases or mental illnesses as punishments. These punishments could be for the actions of a family member, or the afflicted individual's actions. The view is very fatalistic in nature; diseases are sometimes believed to be permanent and need to be accepted as one's destiny, as observed during a student's cross-cultural trip to Vietnam. This could affect how many families are willing to join a registry based on a mental health problem that is viewed as one's fate. Also, in some cultures, there is a concern that personal and sensitive information might be exposed, which would bring dishonor to the family. This is a legitimate concern and could impact the number of families willing to join a registry (Giger & Davidhizar, 2008).

In a Communist country, organizations may experience stricter regulations. With many of the potential clients living in villages without a specific mailing address, it could be difficult to keep in contact with patients. This would also be a concern for clients who lack phone numbers, e-mail addresses, or even a permanent address.

Financial Projections for the First Three Years of the Project

Information regarding the potential costs associated with developing an online registry in Vietnam was gathered through research of similar, successful operations throughout developing countries. Specifically, in Vietnam, project Optimize worked with government and software partners to help introduce a digital immunization registry (PATH, 2013). "This registry allowed the health system to better track children due for vaccinations and shortened the time required for recording and reporting immunizations compared to the existing paper-based registry" (PATH, 2013). The purpose of this immunization registry is similar to the goal MEDRIX has set to track children effectively and easily throughout the country who have been diagnosed with autism.

A cross-cultural nursing trip to Vietnam revealed that most health clinics already have access to the Internet and desktop computers, as well as health care workers who are familiar with mobile communication technologies. This information is helpful in assessing the initial start-up costs associated with the implementation of the on-line autism registry.

Project Optimize implemented the immunization registry at 17 commune health centers in Vietnam. The cost of implementation was reported at approximately \$1,500 per facility with a grand total of \$27,000. It is estimated that training and software development will account for 70% of the total investment (\$18,900), 20% (\$5,400) for the purchase of equipment, 7% (\$1,890) for planning, and the remaining 3% (\$810.00) for personnel (Robertson, comp., 2013).

If government approval is granted for operating an autism registry similar to project Optimize, there will be ongoing direct and indirect costs to consider. Personnel to monitor and manage the registry will continue to be a need. Another ongoing cost involves software and hardware maintenance, i.e. tools needed to implement upgrades and debugging of the system. Advertising and education will be an essential element to the registry's success and will require time and funding as well. An example of an indirect cost includes the need for at least one central hub facility for administrative personnel and organizational purposes. Through a contract with the PATH organization, a fixed building costs (including utilities) of up to 50% of one of their existing facilities can be negotiated.

Though this will be a non-profit project, it is important to think of revenue as money being brought in from outside sources. It is imperative for this registry to seek funding from government and philanthropic donors. Revenue for this project can be measured through monetary (i.e. grants and loans) and non-monetary (i.e. in-kind gifts and volunteer/service) means.

Development and Demise Schedule

The development of the strategic plan was initiated during January of 2014, and is scheduled to continue until December of 2015. Throughout the duration of the strategic plan, if another organization is found to create a similar competing registry project or the registry is deemed to be illegal, then the demise schedule will commence over a time span of one month. Various demise tasks may include, but are not limited to: directing staff to tie off communication with other parties involved with registry development (such as government or technical support members) and directing funds into a central account to be regrouped.

Section 5: Action Implementation Plan

Action Implementation Timeline

Phase 1: Planning (Jan-April 2014)
<ul style="list-style-type: none"> • Define the scope of the project • Identify sources • Develop a list of cooperating organizations • Determine data to include • Gather input on desired functionality
Phase 2: Analysis and functionality (May-Oct 2014)
<ul style="list-style-type: none"> • Acquire data from external sources • Analyze for potential gaps and duplications • Draft requirements
Phase 3: Development (Nov 2014-Oct 2015)
<ul style="list-style-type: none"> • Develop technical specifications • Developing strategies to prevent duplication and gaps in registry • Design the online interface • Test and evaluate system internally • Test externally and gather feedback • Incorporate feedback into production
Phase 4: Implementation/ production (Nov-Dec 2015)
<ul style="list-style-type: none"> • Announce availability of registry for use • Assess the success of the registry • Continue to refine duplication and gap detection • Maintaining and updating the registry

Assignment of Responsibilities and Accountability

MEDRIX has limited full-time staff and carries out much of its work through partnerships and volunteerism. It is for this reason that it might be advantageous to consider creating a volunteer or unpaid internship position solely to help in the completion of this project due to the scope and length of the tasks required for implementation. This intern, or volunteer adjunct assistant, would be accountable to the Executive Director, LaRelle Catherman, and the board of MEDRIX. As a list of cooperating organizations is developed, tasks can be delegated to partners for completion, with the responsibility of communicating with partners and monitoring progress of tasks, being assigned to the volunteer coordinating aspects of the project (MEDRIX, 2014).

Key Policies, Procedures, and Rules

In order to have an effective registry, there needs to be a set of policies or rules to govern it. These policies will serve as a framework for the management and organization of the registry. One important guideline is to distinguish what the registry will be used for, specifically. The purpose of the autism registry in Vietnam is to compile a database of children with autism to ensure an easier, more effective way provide recourses and help schedule appointments for those individuals. It is also necessary to develop a set of parameters identifying who qualifies to be included in the registry. The registry would include individuals up through age 18 that are diagnosed with an autism spectrum disorder, since a primary clinical focus of MEDRIX includes the pediatric setting. This registry is to be used by hospitals at the district level to provide a standardized way of relaying information to the province, and so on all the way up to the national level. This will speed up time that the information is relayed and provide a more accurate database. Clearly defining what the purpose of the registry is, who can be included, and how it

will be used and implemented, helps to create a system that can be used efficiently and effectively by the people in Vietnam.

Marketing, Advertising, and Public/Constituent Relations

When creating a new program, such as an autism registry, it is a necessity to build relationships and partner with other organizations and possibly governmental agencies to get the project off the ground. One organization that may be beneficial to partner with includes PATH, specifically with their project Optimize. “In Vietnam, project Optimize worked with government and software partners to help introduce a digital immunization registry” (PATH, 2013).

Partnership with this organization could open up doors to help start an electronic registry for autism since PATH already has an established program, and is interested in expanding the current registry to include other health issues. Because project Optimize already has a working registry in place, marketing might include providing informational materials about the autism registry at the local level including district hospitals as well as the hospital staff. Developing this registry would also strengthen the relationship between MEDRIX and the Ministry of Health in Vietnam, which could help with current and future projects.

Outcomes Expected

An autism registry in Vietnam will have a positive impact on individuals with this disorder when it is finally launched. With a plan in place, it is expected that within two years, there will be a functional autism registry being utilized by every level of the health care system in Vietnam. This will help to connect individuals who are included in the registry with resources that are available to help them and their families manage their disorder. Also, the electronic format of the registry will make it quicker for data and information to be analyzed, interpreted, and shared.

Section 6: Methods of Evaluating Achievement of Goals

Specific metrics for the strategic and operational goals of the autism registry are crucial to the success of the project. Goals should be evaluated in four domains: production/operations/impact, financial performance, marketing/advertising/public and constituent relations, and timeliness.

The strategic goal is to identify an existing medical registry in Vietnam. To evaluate this goal in the production domain, only one question remains: has a currently operating registry been identified? A reasonable financial evaluation of this goal is to verify that the current registry was identified without cost to MEDRIX. Because this goal is internal to the organization, a marketing evaluation is unnecessary. To achieve the implementation of the autism registry in a timely manner, the strategic goal should be completed by April 30, 2014.

The operational goal has two facets. It is to be able to secure both funding and legal permission to implement and maintain an autism registry in Vietnam. This goal can be evaluated in the production domain by whether the group has verified whether an autism registry is legal in Vietnam, given the tight control implemented by the Communist government and whether the appropriate government agencies from which to seek permission have been identified. Financially, specific funding sources for the development and maintenance of the registry should be identified. A marketing evaluation of this goal is to verify marketing for funding sources has reached an appropriate target audience. Both facets of this goal should be accomplished by October 31, 2014.

Conclusion

Creating an autism registry in Vietnam will provide better tracking and treatment of pediatric patients, and hopefully, a higher quality of life. It is clear that a sustainable health care

related registry currently exists in Vietnam, and the previously discussed financial and organizational parameters can be used to guide an autism registry, specifically. With a registry such as this, the Vietnamese government will be able to provide better care for its upcoming generation.

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