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Humanoid Research on Brain-Impaired Children: Comparative Policies

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Abstract

The purpose of this paper is to provide rigorous, narrative and in-depth scrutiny on the policies in humanoid research on brain-impaired children. In the health care industry, the use of therapeutic robots in rehabilitation has been significant. Thus, the paper will explore the fundamental, benchmarking issues of similar policies and guidelines of other nations to suit Malaysia's research environment. The methodology for this study will employ library research and content analyses including insider input. The four policies are; the Malaysia National Welfare Policy (1990), the Malaysia National Social Policy (2003), the Malaysia National Policy for Persons with Disabilities (2007), and the Malaysia National Plan of Action for Persons with Disabilities (2007-2012). From the five policy papers, it is expected that any research projects involving children with mental disabilities will require the compliance with the current statutes and policies but should there emerge a unique case, an extension to one of the policies would have to be undertaken to circumvent ethics in research practices. Also, the narrative outcome from this scrutiny includes a discussion of the relevance of these policies.

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1. Introduction

The number of children born with various mental or brain impairments have increased in tandem with the world population explosion. The care needed for these special children would depend on their disability. Therefore, the quality of pediatric-centered care in special institutions require innovative technologies [1] to assist with the augmentation, improvement and development of the children's education, social and hygiene skills, among others.

As again noted by Net *al al*, [1], assistive robots, which in this case are the humanoids, will focus on aiding patients with disabilities. The motivation for the study involving human beings require a policy guideline to ensure ethical practices in Malaysia.

2. Background

In the past decade, research projects on neuroscience or brain science have been tremendous [2]. It is also anticipated that robots will be commonplace [3] in any domestic and healthcare settings. As opined by Kernaghan [3], a diverse assortment of robots, with varying purposes, capacities, forms and sizes is emerging with significant implications for policy, service and regulatory responsibilities of government". Therefore, it this statement is applied to the current Malaysian scenario on the use of humanoids for brain-impaired children, certain policies and ethical standards have to be in place before, during and after the research projects are conducted. Aside from these, contemporary public sector ethics such as personal moral responsibility, privacy and accountability are crucial to the emerging fields of ethics and policies [3] in humanoid robot research.

Humanoids, is a type of assistive robot where the research projects within this area is rapidly growing. The use of humanoids or assistive robots in health care settings, particular for brain-impaired children, is seen as one of the most important applications of robots [1]. Notwithstanding, humanoids for education [4] and skill development and augmentation are equally as important.

3. Statutes and Policies, Malaysia

Before the conduct of the actual study, the statutes and policies of the five identified has to be described.

3.1. Malaysia National Welfare Policy (1990)

As stated in the Caucus Report [5], Malaysia's concerns for the "optimum development of its children is reflected in the numerous socio-economic policies and plants which seek to create a conducive and enabling environment that are sensitive to the children's needs, be it normal or disabled children". The policies and plans are; the Five Year Development Plans, the New Economic Policy, the National Development Policy, the National Education Philosophy, the National Welfare Policy and the National Social Policy. Anyhow, the National Welfare Policy "aims to create a society whose members are imbued with the spirit of self-reliance, enjoy equal opportunities and care for one another especially for the less fortunate". This can be construed to include mentally-challenged children.

3.2. Malaysia National Social Policy (DSN) (2003)

The general objective of the National Social Policy is to "ensure that every individual, family and community, regardless of ethnicity, religion, culture, gender, political affiliation and regions can participate and contribute to national development and achievement of well-being on an ongoing basis". Specifically, the assurance that the basic needs of the individual, family and community are fulfilled. In relating objective one to the study, the policy with the scope's realms are already in place and therefore, the outcome of the study should have significant impact for the project to continue and progress. The second objective is to build and empower human beings throughout their life.

This assurance is part of the study's objectives where the use of humanoid is necessary to assist practitioners and parents to train their disabled child so that he or she can continue to lead a normal life past adulthood. The third objective then is to strengthen and develop social support systems and services. When mentally-disabled children are given adequate training in social skills and hygiene, in a way, this provides sufficient progress for normalcy in life. Lastly, the fourth objective is to generate multi-sector synergies. This is the capstone part where private institutions and some federal-funded agencies may be able to afford having humanoids to assist with therapy. As such, the private and public institutions should work together to ensure that these minorities, the mentally challenged children are given every opportunity they can to assimilate with other children without any discrimination.

Nevertheless, the policy statement for DSN is a that it is "a social development policy based on good values and the improvement of human potential to achieve unity and social stability, national resilience and the well-being of a progressive and robust Malaysian society".

3.3. National Policy for Persons with Disabilities (PWD) (2007)

The Policy for Disabled Persons (PWD) is "based on the concept of equality of rights and opportunities for PWD to participate fully in society. This policy also emphasizes on human rights values such as integrity, honor and independence that will enable them to live independently". Although this policy is titled differently, some aspects of the content are almost similar to DSN. However, the difference is in the four object, the first is to provide recognition and acceptance of the principle that people with disabilities have the same rights and opportunities for full participation in society.

To reiterate, no matter the physical and mental ability of a Malaysian citizen, he or she deserves to be given the same treatment as a normal person. The second objective is to ensure that PWD enjoy the rights, opportunities and equal access under the law of the country. This means that as a citizen of Malaysia, the same rules and regulations apply to persons with disabilities. To some extent this is true but handicapped persons are given special privileges that normal ones are not accorded such as special parking places, etc.

Nevertheless, the third objective is to eliminate discrimination against a person because of his or disability while the fourth objective is to educate and raise public awareness about the rights of disabled people.

In the policy's strategy, it is important to note that rehabilitation of the disabled is emphasized through the increase in the effectiveness and expansion of existing rehabilitation programs for the disabled as well as the creation of new rehabilitation programs for the disabled in line with current developments. Consequently, other supportive strategies are included such as human resource development, social activities, community involvement, research and development, housing and employment.

3.4. National Plan of Action for Persons with Disabilities (2007-2012)

The Malaysian government's commitments in promoting and strengthening this minority group, the National Plan of Action for Persons with Disabilities was established with two kinds of empowerments; the first is economic empowerment and the second, is self-advocacy. However, the challenge for the government is in identifying the individuals for proper assistance, therefore, there is a need for voluntary registration of persons with disabilities (PWD). This is important as the 'registration of PWDs will enable the government to recognize and identify the disabilities in order to plan and formulate appropriate programs for the development of the PWDs." In registering the PWDs, there are seven categories of disabilities that are specifically stated. They are:

- i) Visual impairment
- ii) Hearing impairment
- iii) Speech impairment
- iv) Physical disabilities

- v) Learning disabilities
- vi) Mental disorder, and
- vii) Multiple disabilities.

In the government's commitment to ensure that the PWDs are given their due rights, the reiteration of international commitments are included such as:

- The adoption of the Asian & Pacific Decade of Disabled Persons (1st decade: 1993-2002 and 2nd decade: 2003-2012).
- ii) The signing of the Proclamation on the Full Participation and Equality of People with Disabilities in the Asia and Pacific Region on May 16, 1994.
- iii) The recent adoption of the new Asian and Pacific Decade of Disabled Persons, 2013-2022.

Other international commitments include the Malaysian government's endorsement of the Biwako Millennium Framework for Action (BMF) towards an inclusive, barrier-free and Rights Based Society for People with Disabilities in 2002 and the Biwako Plus Five (in 2007) - to be fully committed to promote an inclusive, barrier-free and rights-based society for PWDs in the country.

Based on the above subscriptions, in November 2007, Malaysia formulated the PWDs Policy and National Plan of Action with the following details:

- This policy recognizes that PWDs are free from any physical, social, economic, cultural as well as attitudinal barriers
- ii) It will be used as a foundation to ensure PWDs enjoy their full and effective participation in the society on an equal basis with others.
- iii) 15 strategies underlined in the Policy (including advocacy, accessibility, education, health, employment, social support, etc.)

Consequently, in December 2007, the PWDs Act 2008 was passed by the Parliament and came into force on July 7, 2008. It is this Act that provides for the registration, protection, rehabilitation, development and well-being of PWDs, the establishment of the National Council for PWDs and for other related matters. Also, the Act is aimed to ensure that the rights, interests and welfare of the PWDs in the country are protected. Finally, it is important to note that the policy was drafted after taking into consideration all provisions provided under the United Nations Convention on the Rights of PWDs.

4. Children with Special Needs (Program)

To quote the Caucus Report, [5], "since 1986m there has been a move towards improving the outcome of children with special needs". For this paper, this can be implied to include mentally and intellectually-challenged children. "The quality of life of children with special needs has markedly improved with the provision of early Intervention Services at the primary health care level. The Program of Care for Children with Special Needs provides rehabilitation services for children with special needs from birth to 18 years of age.

In relating this to the primary schools with special integrated classes, the maximum age limit for children with disabilities is 15 years. After that, they are promoted to secondary schools with special classes. To continue, "The Ministry of Education is responsible for providing education to children with special needs. Efforts have been undertaken to increase educational opportunities for these children". In relation to the project and purpose of this paper, some of the children in the special integrated classes suffer from mild brain impairments such as slow learners and dyslexia. From the researcher's observations, children in these categories are physically normal but are not suitable to be put with the mainstream classes as they are laggards. Hence, "the establishment of special schools

for the blind and deaf as well as the integration of children, especially those with learning difficulties, those who are visually impaired and those who are hearing impaired in regular schools. There are about 13,583 children who benefitted in this program in 2003 whilst those disabled children who cannot attend the formal education system will be absorbed into the community-Based Rehabilitation (CBR) program".

Consequently, the "Integration of children with Disabilities in the society through community organization is greatly emphasized. CBR is a strategy with the community development for the rehabilitation, equalization of opportunities and social integration of people with disabilities (PWDs), It is implemented through the combined efforts of PWDs, their families and communities and appropriate health, education, vocational and social services. CBR programs have proven to be very effective in helping PWDs and their families to cope and work together towards a better quality of life for the PWDs".

In addition, "The CBR program is a preferred alternative to institutional care since it provides decentralized rehabilitation services and early intervention for persons and children with disabilities in their own community. It helps to ensure the acceptance and social integration of persons with disabilities, including children, as well as providing them the opportunity to develop their abilities and skills to their full potential, leading to a meaningful life. As a result, CBR prevents the separation of persons and children with disabilities from their families and communities and facilitates the evolution of a caring Malaysian society".

Moreover, "with the signing of the Convention of the Rights of Persons with Disabilities in 8 April 2008, Malaysia is giving greater commitment to the development of PWDs which include children with disabilities. The enactment of Persons with Disabilities Act 2008 which was enforced in 7 July 2008 will give greater emphasis on the rights of the PWDs and the concept of inclusive, barrier-free, right-based society".

With this policy in place, there is no doubt that better developments in assisting children with brain and intellectual impairments have started on a positive footing.

5. Persons with Disabilities Act (2008)

"The Persons With Disabilities (PWD) Act was passed in Parliament (National Assembly) on December 24, 2007 and was gazette on January 24, 2008 and came into force on July 7, 2008. The Persons With Disabilities Act provides for the recognition of the rights of disabled people and PWD concept is changed from welfare concept to right-based concept. The Act also allows PWD to have equal right to opportunities and full participation in society on par with other community members. The PWD Act also provides for matters concerning the registration, protection, rehabilitation, development and wellbeing of PWD". Similarities on the goals are observed here too.

6. Medical Device Act (2012)

According to Kherk [10], "The Medical Device Act 2012 (Act) and Medical Device Regulations 2012 (Regulations) came into operation on 1 July 2013. The Act is the product of the efforts of the Ministry of Health to implement a regulatory framework for medical devices, an area previously not regulated in Malaysia. The Act seeks to address public health and safety issues and facilitate medical device trade and industry. For the purpose of this paper, the term 'device' is understood as humanoids. Hence, in introducing humanoids in the rehabilitation and social skill improvement of mentally challenged children, the Act regulates the device mentioned, that is, "the Act will impact players in the medical equipment industry in Malaysia such as the:

- i) Establishment License
- ii) Registration of Medical Devices
- iii) Export Permit
- iv) Designated Medical Device Permit
- v) MedCast
- vi) Confidentiality of Registration

- vii) Manufacturer's general obligations
- viii) Advertising of Medical Devices
- ix) Duties and obligations, and
- x) Offences by Bodies Corporate

To summarize, "the Act provides much needed regulation in the area of medical device manufacture. Players in the industry should begin altering their processes and expectations in order to be compliant with the Act now that it is already in force. It is hoped that the advent of the Act will result in smoother conditions for trade as well as greater safety from a public health perspective".

All in all, the introduction of humanoids to sensitive establishments involving children who are mentally challenged requires the approval of procedures as obligated by the various statutes and policies.

7. Comparison: Other Foreign Policy

In comparison, one foreign policy papers' perspectives on using humanoids for social and developmental skills of children that are mentally and intellectually challenged are shown.

7.1 South Korean Robot Ethics Charter (2012)

As pointed out by Akiko [11], the Charter was drafted "in order to prevent social ills that may arise out of inadequate social and legal measures to deal with robots in society". What this means is that the robots are protected and given rights like a human being. Anyways, there are three Parts to the Charter:

- Part 1: Manufacturing Standards
- Part 2: Rights and Responsibilities of Users/Owners
- Part 3: Rights and Responsibilities for Robots

In circumventing this Charter with that of the paper's purpose, Part 3 will be elucidated. There are two sections here which are quoted verbatim [11]:

- Sec. 1: Responsibilities of Robots
 - i) A robot may not injure a human being, or through inaction, allow a human being to come to harm
 - ii) A robot must obey any orders given to it by human beings, except where such order would conflict with Part 3 Section 1 subsection "I" of this Charter.
 - iii) A robot must not deceive a human being.
- Sec. 2: Rights of Robots

Under Korean Law, robots are afforded the following fundamental rights:

- i) The right to exist without fear of injury or death
- ii) The right to live an existence free from systematic abuse.

From the Charter, we can deduce that Sec. 1, part (i) can be used for the purpose of research involving humanoids and special needs children.

8. Conclusion

Although humanoids or assistive robots are not specifically mentioned in the policy papers, there is a need to establish one regulation for research projects involving these technologies and the special children. This will lay the ground work for ethical conducts as more and more research interests within this scope of special needs children

emerge. However, in prescribing a specific policy paper, there is none that is currently suitable for Malaysia as noted in the Medical Devices Act. It is recommended that one general guideline be drafted for the benefit of other similar and future research works.

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