

# Personal Learning Journey In Special Education

Norman Kee Kiak Nam

## **Abstract**

This paper is written for parents and by a parent with special needs children and also in fulfilment of the module MSE802 : Issues and Trends in Special Education of NIE. It is essentially a reflection and account of the learning journey that surfaces important points for consideration here in Singapore, based on research findings. It begins with examination of how our psyche of special needs people are developed by our environment, our personal experiences and how they can be shaped using my personal sharing to illustrate. The intention here is to understand how our prejudice & attitudes are shaped with implication to how we should then endeavour to develop the desired perception. As I am basically interested in post-school follow-up and post-parents follow-up, I will then share my findings on interviewing different stakeholders (educational psychologist, social worker, executive director and parents with special needs children) to compose a realistic picture of the current situation in Singapore and the valuable insights and needs surfaced. Consequently, the need to focus first on post-school follow-up is evident as it is more urgent and a prerequisite before post-parents follow-up needs to be considered. Thus, I have gathered some significant research literature on the vision and best practices to seriously consider for guiding our further actions on post-school follow-up. The significance is to learn from the mistakes of well-meaning endeavours and focus on what has been found to work and worthy of consideration for adoption here. Finally, I would like to share my action plan of what I will do, after all the learning, to hopefully and God willing, make a difference for all parents with special needs children for a holistic post-school follow-up program.

## **1 Positioning of Self**

### ***1.1 Past***

If we are to examine ourselves honestly, we would have already formed our concepts of disability, even though, we may or may not have personal encounters with people with disability. How all these meanings are made, can be best explained using the model of human action and learning (Lim & Choo, 2002). Essentially, there are two contexts where meaning is made. One is self and the other social context. In self context, my meaning of disability was made by my personal encounters of people with disability (Personal Practical Knowledge) and the influences friends and people around me project to me regarding people with disability

(Worldview). My personal practical knowledge about disability when I was schooling, was generally from a distance. I was generally uninterested, as I was more concerned with academic achievement and climbing the academic ladder. My parents have taught me to be caring and considerate to people with disabilities and not to laugh or join others in laughing when seeing disabled people. I did notice when in primary school, that one had polio and needed metal crutches and support to move around. My impression of him was that he was strong-willed, loud in talking and insistent in his ways. His mother was always around during his recess time and assisted him tactfully, careful not to injure his ego or self-will. The worldview then on disability was that they need charity organisations' assistance and much help in getting along in society. It is normal to see children making fun of people with disability or to stare and comment on them. I guess in their spontaneity and innocence and even mine, it did not occur to us then, that it was cruel and unkind. After all, they were born with it and did not ask for the condition and the least we can do, is to show some consideration and kindness. I believe, school and the public should be taught what to do when encountering people with special needs and how best to understand and appreciate the situation.

I recalled the social context of public knowledge on disability education then, was focussed on the blind, deaf, spastic and the physically handicapped. Perhaps, some are from the media, but generally most comes from looking at the flag day stickers information revealing the voluntary welfare organisations (VWO) concerned or being directly involved in compulsory selling of flags. Regretfully, I did not have any significant human action other than contributing a small token on flag days or being involved in selling of flags.

The significant change occurred only when I became a parent and learnt that my three sons have autistic spectrum disorder (ASD) of different degrees. The need to learn and understand ASD became imperative and urgent, so as to seek out effective intervention strategies, to help in their development. Since then, together with my wife, we have been attending seminars, courses, workshops and reading to improve our knowledge and understanding of how to help our children with ASD. Learning that the first six years are very significant period of the child's development to make a difference, my wife has stopped her teaching career to focus on intervention strategies on helping our children, of which I am most grateful and indebted.

## ***1.2 Present***

The impact of the course MSE802 : Issues and Trends in Special Education on me can be summarised according to the activities below. The value here is to appreciate and comprehend how the diverse activities planned can be used to shape understanding and appreciation of special needs people.

### **1.2.1 Discussions and sharing by fellow course mates**

The honest and frank sharing by fellow course mates (teachers and educators from MINDS, Margaret Drive Special School, pre-school, primary & secondary (gifted, mainstream)), with and without direct experience in special education, was enlightening and insightful. The sharing reveals the realities and plights of teachers, educators and parents in helping people with special needs and their noble intention to seek better ways to help them. The peek into some of the programs and services implemented and the comments by all, was an eye-opener. Many of the issues surfaced, were being looked into as part of their assignment like mine. Perhaps, with permission, the learning's can be shared when available.

### **1.2.2 Visit to Red Cross Home of the Disabled**

The visit can be described to have deep emotional impact on myself and others in the course. Meeting people with cerebral palsy of different ages from five years old to more than sixty years of age, lying helplessly, in wait for some kind soul to talk to or give needed physical positive strokes of care and concern was very forceful emotionally. It provokes a deep sense of need to help them in some way and reveals a neglected and ignored group of disabled people in society. It has left deep impressions that something needs to be done. My personal after thought of the visit is the need to improve their daily quality of life, in terms of friendships and meaningful activities for each day. To put things in perspective, Red cross is already doing a fantastic job of taking care of all their basic needs with the resources they have. Perhaps, others including myself should look into how we can make a difference to their lives that will further improve their situation in a practical and lasting way.

### **1.2.3 Sharing by Mrs Margaret Goh (Parent with Down syndrome)**

The salient points are that she was shocked and impacted, not so much by the news of the disability of her child but by society treatment of her and her child. This includes some medical professionals she encountered who seem bent on wanting her to let her child go rather than helping him.

The candidness of the need to educate the public on what to do when meeting people with special needs is clearly illustrated by her sharing of eating in public places, where the next table people keep on commenting on her child, even though all their food were already on their table and the frequent stares was uncalled for.

The drive, persistence, nurturing environment, fearless confrontation & innovative ways to resolve problematic obstacles of her son's learning and ever search for ways to help her child, clearly illustrates the

critical component of parental involvement, to yield significant leaps of development, due to personal involvement in early intervention. She has beautifully painted significance of parental involvement from her sharing and personal videos of her son's performance.

#### **1.2.4 Dr. Wong Meng Ee (Person with Sight Impairment)**

I cannot help but look with admiration and salutation to Dr. Wong, on his exemplary example and role model of an able person with nuisance of sight impairment. His lecture and sharing of how he overcame and circumvent challenges posed by society on his visual impairment, to be an active positive contributing citizen, well included in society was uplifting and inspiring. In no uncertain terms, was the clear need for self-determination and strong family support important factors for a significant future. He is now working in National Council of Social Service (NCSS) as a principal executive and actively contributing to adult disability services.

#### **1.2.5 Ms Jaspreet (Adult with Down syndrome)**

She certainly projects herself as a highly commendable and independent woman, living with Down syndrome nuisance and is an active contributor to society, working as a teacher in a kindergarten. Her exposition of her inner thoughts, reveals insight on the patronising stereotypic view of Down syndrome people, as stupid and incapable of intelligent work. She detest and refutes this thinking, as she is an active example, that the assertion is nonsense, prejudicial in view, and patronising. She implores people to be patient with Down's syndrome people, by giving them more time to comprehend instructions and providing clear instructions without hidden assumptions or skipping steps. She has certainly portrayed that she is every bit a human with feelings and rights, and should be respected as everyone else, without patronising behaviours.

#### **1.2.6 Dr. Balbir Singh (Father of Jaspreet)**

My personal impression of his sharing is a committed father who would go all out to help his daughter. The highly analytical and clear thinking medical doctor shares his insightful parental views of the reality and his personal quest to both nurture and provide opportunities for truly inclusive curriculum in school, at home, with relatives and with society (local and overseas) for her daughter with Down syndrome. The passion is so great that he leads the Down Syndrome Association here as the president and advisor and founding chairman.

### **1.2.7 Dr Levan & Mdm Thana Thaver (Researchers in Special Education)**

Their sharing of the research findings on “Coping with students with diverse abilities in mainstream schools in Singapore” reveals verifiable realities, that teachers can easily identify with and the state of affairs for both special needs pupils and teachers teaching pupils with special needs in mainstream schools. As the preliminary findings are not yet published, it is only fair to share the findings after publication.

In any case, the research findings will be incorporated into pre-service and in-service teacher training to commence with a pilot in July 2005. Hopefully, the findings and recommendations, with local data, will be more convincing than overseas materials and perceivably equip teachers with realistic appreciation and expectation to cope better in their teaching career with pupils of special needs.

Please note that Dr. Levan Lim co-published with Dr. Marilyn Mayling Quah (Lim & Quah, 2004) a book “Educating Learners with Diverse Abilities” that is written with the local Singapore context and I would highly recommend you to acquire and read it to learn of the different local services from VWO and desirable curriculum goals to work on for people with special needs.

### **1.2.8 Videos/Presentation on Institutional Era, Christmas in Purgatory, Sue, Peter, Visions, etc.**

The impact of videos and visual presentation cannot be over-emphasized, as they allow a holistic appreciation of the development of the issues from many angles. Well produced narrated videos and un-narrated visuals (e.g. Christmas in Purgatory), have equally powerful effects and can leave deep impressions in our psyche on disability. Essentially, it shows clearly that neither institutionalisation nor deinstitutionalisation is a panacea to service planning (Levan & Nomanbhoy, 1998; Young, 2003; Tabatabainia, 2003; O’Brien, 2003). Community Membership Era is desirable, but still in its infancy stage with some efforts on paid community builders to facilitate inclusion into the community (Harlon-Simmons et al., 2001).

The video on “Focus Your Vision” is inspiring, encouraging us not to give up, but to think “out of the box” for far reaching outcomes, the key concepts are as below:

1. Keep Your Vision Focused – When we focus our visions, we find their purpose.
2. Stop, Look, and Listen – Great visions don’t leap out to meet us! To find one, we need to slow down and really understand what’s happening.
3. Hold On To The Best, Let the Rest Fall Away. - Intellect helps us find which parts of our visions are really important and which to get rid of.
4. Trust Your Intuition. – If we learn to trust it, our intuition can reveal spectacular visions.

5. It's Not Trespassing To Go Beyond Your Own Boundaries. – Taking risks and expanding our horizons helps us turn visions into reality
6. Make Your Vision Big Enough. – The really big visions should never be focused too tightly.
7. Do You Have Juice In Your Camera? – Juice is passion, the energy needed to realize our visions

Similarly, to maintain a positive outlook in life and to make do with the best we can, the lessons from the video “Celebrate What’s Right With the World” are inspiring. This is especially the case for special education where there are formidable hurdles to clear, to bring forth a better future for those with special needs.

The key concepts are as below:

1. Believe it and you’ll see it.
2. Recognise abundance.
3. Look for possibilities
4. Unleash your energy to fix what’s wrong.
5. Ride the changes.
6. Take yourself to your edge.
7. Be your best for the world.

### **1.2.9 Inclusive Education (Singapore, Brunei Darussalam, Hong Kong, Philippines, China & Queensland)**

From the discussions in class, the meaning between integration & inclusion in education seems to be ambiguous. My understanding of integration is putting pupils with special needs in mainstream class, without any significant consideration or provision for the special needs. Inclusion, on the other hand, involves taking care of the support needs of the disability, such as enlarging notes, teaching materials, presentation materials for the visually impaired and more time given for the reading. The basis for the above interpretation is from understanding educational pedagogy for inclusion using socialcultural theory (Lim & Quah, 2004).

The paper on “Foresight via hindsight, prospects and lessons for inclusion in Singapore” (Lim & Quah, 2004), summaries the lessons for Singapore. I would like to highlight two models of inclusion from Philippines and China. Both consider leveraging on existing school premises to include special education for economic reasons and access to extensive existing education infrastructure for implementation reach. In Philippines, the ‘Silahis Centres’ (‘school within the school’ concept) (Inciong & Quijano, 2004) considers using existing mainstream school with an independent special school within the school premises. The implementation includes

self-contained classes for children with special needs to full inclusion in regular mainstream class within the same school. Essentially it allows the gradation of inclusion depending on readiness.

China on the other hand, adopted the “Learning in Regular Classroom” (LRC), where the child has differentiated teaching with individualised education plan designed in regular classrooms or individual tutoring if whole-class lectures are conducted(Deng & Poon-McBrayer, 2004).

Invariably, parents with special needs children and voluntary welfare organisations are the main driving force for social improvements, especially for special needs people. All the studied countries implement compulsory education (Inciong & Quijano, 2004; Deng & Poon-McBrayer, 2004; Gillies & Carrington, 2004; Leong, 2004; Poon-McBrayer,2004) for all children including those with special needs with the exception of Singapore. Perhaps, with the current rhetoric of the new paradigm on team building instead of Singapore Incorporated and “No One Left Behind” learnt from the speech by Dr Vivian Balakrishnan (Acting Minister for Community Development, Youth and Sports and Senior MOS for Trade & Industry speech at the Committee of Supply Sitting 2005 , 10 March 2005, 5.30 pm), there is hope of the needed change already practiced by other countries. This would be in the spirit of the *Salamanca Statement*, that “ all children should learn together, wherever possible, regardless of any difficulties or differences they may have to combat discriminatory attitudes, to create welcoming communities, build an inclusive society and provide education for all” (UNESCO, 1994:2 cited in Inciong & Quijano, 2004)

### **1.3 Future**

The evolved meaning of person who has a disability is one in which the person has a “nuisance” or an inability or with special needs. Invariably, all with a certain nuisance, will eventually make use of other good faculties or behaviourally, to circumvent their weakness and lead as normal a live as possible. The paper on “Culture and Disability” (Gartner, et al. 1991) describes well this understanding in the Martha’s Vineyard where it was home of the largest community who were deaf. The quote below from the paper aptly articulates this understanding.

*“Most Vineyarders remembered that those who were deaf regarded their inability to hear as a nuisance rather than an overwhelming problem....Most, when pressed on the point, believed that local people, hearing or deaf, preferred to have hearing children, but the birth of a deaf child was regarded as a minor problem rather than a major misfortune.(Groce, 1985, p53)*

Most do not deny the nuisance, but do not accept that they are disabled or handicapped. They are fully human with feelings, dreams, and ambitions and are useful members of community, if given the support and opportunity. This has also been echoed from the sharing of Ms Jaspreet, Dr Wong, Grace Chan(Wong. 2004) and the view of the group of deaf people in the video on “Year of the Patronising Bastards”. Personally, I would like to use the quote below from the same paper which describes it well.

*“The largest single self advocacy organisation of people labelled as retarded calls itself “People First”. Marsha Saxton, a person with Spina Bifida reports, “ As I see it, I’m not lucky or unlucky. I’m just the way I am. But I’m not disabled. I always thought. Or handicapped” (Saxton, 1985, p. 129). Denise Karuth, who also has a physical disability, sounds like a modern day Win(in Margaret Kennedy’s novel, Not in the Calendar) when she writes. “Put your handkerchiefs away. I’m a lot more like you than you possibly imagine” (Karuth, 1985, p. 12). The message in each of these instances... is that a disability is only one dimension of a person, not all-defining and not inherently a barrier to being recognised as fully human. (p. 7)*

As I see it, the future of a person with an inability depends on a large extent on the following:

- a) early diagnosis, knowledge of condition & early intervention (Maurice et al, 1996; Greenspan & Weider, 1998; Mesibov & Howley, 2003; Kranowitz, 1998; Hannaford, 1995)
- b) parents quick & honest acceptance, learning of condition and intervention methods, resourcefulness, determination, perseverance and continuous active involvement in nurturing and learning environment for holistic development and opportunities. This is evident from all the verbal sharing of Mrs Margaret Soh, Dr Wong and Dr Balbir Singh. The “Amazing Grace” article (Wong, 2004) also clearly documents the elements needed and my personal experience as a parent with autistic children to more than confirm the assertion.
- c) Self determination of person with an inability to overcome weakness and move on in life(Field et al., 2003; Hellendoorn & Ruijssenaars, 2000)

A notable missing aspect in the curriculum is teaching and facilitating how to build lasting friendships and relationship (Sumarah, 1987; Pottie & Sumarah, 2004)of people with special needs, which is very important for healthy development of the person’s emotional and physical well being.

The hindsight and foresight from continuous and life-long learning from research literature and in practice would be one of the future habits for me to cultivate for effectiveness. For example, in a “Review of Self-Determination Literature” (Malian & Nevin, 2002), eight types of curriculum for self-determination were

reviewed. Useful comments and sources for further information were provided. Essentially, the learning from research literature, empowers me to consider and deliberate on which curricula strategy on pedagogy on self-determination is viable.

## **2 Identifying Issues**

As a parent of three sons with autism spectrum disorder of different degrees, I am compelled with my wife to learn and discover what happens when our child leaves the school system. Our other concern is what happens when we have left the world and are not physically around to help them. I believe these two questions are also in the minds of most parents with children of special needs. The issues can thus be framed as “Vision of adults with special needs and their life after parents have passed on”. Interview and questionnaire were developed, to elicit views from educational psychologist, social worker, parents and executive director of Rainbow Centre. The questions were pilot tested with my wife on relevance, clarity, sensitivity and appropriateness to the different roles. Interview protocol of calling, explaining and getting a voluntary participation was done prior to interviewing. The details and results of the interviews are as below:

### **2.1 Educational Psychologist**

Q1. What are the primary skills set taught in the curriculum that would prepare them for the next learning institution which would also help them in their adulthood?

- Life Skills with emphasis on
  - Work habits (length of time to stay on the task 4 hours goal)
  - Follow expectations of adult via scheduled structured task (prerequisite for employment considerations)
  - Adapting to changes

Q2. What is the main goal of educational psychological assessment? What are the skills you are focusing on?

- To assess what should be the Individualized Education Plan (IEP) and to report accordingly on suitability for placement into different organization.

Q3.: How do you carry out an assessment on the child?

- By following standardized test with modification if needed.

Q4. Is there any other assessment in addition to this form to give a fuller picture of the child’s ability?

- Teacher and parent’s feedback.
- Personal observation.
- Separate sessions if child shows signs of stress making assessment inappropriate.

Q5. Does the school have a follow-up program after the child leaves for the next institution to facilitate and help in their transition? Do you track what happens to the children after leaving for other institution?

- No
- Adhoc basis and by chance meetings
- Would be good to have longitudinal tracking

## 2.2 *Social Worker*

Q1: What kind of future, as in jobs, do ASD adults have in Singapore? What is the reality like?

- Mainly sheltered workshops.
- Financial help but not enough for independent living
- Jobs not easy to come by but there are employment agencies like BizLink.

Q2. Who can they turn to for help if they are in trouble (e.g. job, finance, social and integration problems) that will oversee their well-being long-term?

- Parents, friends and VWO

Q3: What are the options available and help for ASD adults when their parents have passed away?

- Homes
- Need to know VWO to help in referral
- Hospitals can refer

## 2.3 *Parents*

Q1. What do you hope for your child with special needs when he becomes an adult?

- Meaningful and quality living
- Job in sheltered workshop
- Tracking and overseeing of well-being by someone

Q2. What do you think need to be in place for this to happen?

- Enough sheltered workshops for jobs
- Respected, accepted and assisted in dignified ways

Q3. What do you think can be done for people with special needs when their parents have passed on?

- Homes with trustworthy care, provision and protection
- Trust worthy relatives

Q4. What do you think can be done now to ensure that it will happen?

- Ensure enough homes that are credible

- Tracking to ensure knowledge of status of well-being
- Consolidation of information for help sources and sharing of this information to all
- Link up with VWO to ensure continuity of help.

#### **2.4 Executive Director**

Q1. What are the primary skills set taught in the curriculum that would prepare them for the next learning institution which would also help them in their adulthood?

- Focus of curriculum is on independent skills (e.g. social, emotional, cognitive, transition) primarily to prepare them for primary school.
- Whether they will move to the next institution depends on their level of development, availability of places and admission criteria
- If no places, must wait for services to be available

Q2: What are the prospects and realities of ASD adults in Singapore?

- Dim and sad situation
- No proper co-ordination of services
- No clear direction or paths for referral
- Known official roles : MCYS for pre-school and adults. NCSS and MOE for school going children. No macro view planning from cradle to grave services is known.
- VWO has suggested MOE to take over special education and not as present situation of segregation. However, MOE stated that they do not want to dampen spirit of voluntarism and that VWO are doing a good job.

Q3. What are the options available and help for ASD adults when their parents have passed away?

- Dependence on siblings & relatives

Q4. Does the school have a follow-up program after the child leaves for the next institution to facilitate and help in their transition?

- Assessment & teacher's report send to next institution
- Open and happy to sharing child's profile with teacher in next institution if institution is receptive
- Open to teacher either going to next institution to share or receiving the next institution teacher to be briefed.

## **2.5 *Learning from the Interviews***

Generally, the curriculum is geared towards independent living and meeting the criteria for the next receiving institution. In terms of post-school follow-up, the number of services is limited and outlook is dim for adults. With regard to post-parents follow-up, dependency is on siblings and close relatives. The safety net of homes is only via the recommendation of VWOs or hospitals. There is clear lack of tracking the individual with special needs and meeting the needs from cradle to grave. It appears that no governmental authority is taking responsibility for accounting the welfare of those with special needs and checking on their status, although there is an initiative now in NCSS to collect case notes and tracking individuals from the VWOs. The parental interview findings concur with published research findings (Whitney-Thomas and Hanley-Maxwell, 1996 cited in Kohler & Field, 2003; Blue-Banning, et al., 2002) on parental concerns for children's transition needs, such as economic self-sufficiency, expanding social networks, and vocational and residential options, as well as the importance of school personnel in assisting them in addressing these concerns.

### **3 Researching the Identified Issue**

I have decided to narrow down the identified issue to post-school follow-up only, as it is the immediate need. The approach adopted is firstly, to determine what should be the vision for post-school follow-up, so that it can guide the search of the “how” to attain it. Subsequently, it would be strategic to learn how others have effectively initiated the paradigm shift towards the goal. This will also serve as basis for my action plan.

#### **3.1 Vision**

From the readings, I would endorse the community membership model for post-school follow-up (Lim & Nomanboy, 1992). This involves inclusion of all persons with disabilities regardless of current skills or deficits, with emphasis on human relationships and person-centred approach, whereby supports are built around a person’s needs. The focus would be on utilizing natural family and community supports, cultivating informal relationships and networks and honoring greater consumer autonomy. Essentially, the envisioning of meaningful living with active and contributory citizenship in its own right, in a web of community care, with professionals overseeing needs.

#### **3.2 Effective Transition Practices Framework (Kohler & Field, 2003)**

To move towards the vision, a proven transition framework needs to be adopted. I will adapt the transition practices framework proposed by Kohler & Field(2003), which organizes five categories for post-school follow-up transition as below:

1. Student-focused planning to be adapted as Person-Centred Lifestyle Planning Model
2. Student development
3. Interagency and interdisciplinary collaboration
4. Family involvement, and
5. Program structure and attributes

#### **3.3 Student-focused planning /Person-Centred Lifestyle Planning Models (Lim , 1998; Lecture handout of Dr Levan)**

The planning can be facilitated by answering satisfactorily the five questions below in the five areas which are indices of desirable life.

1. Community Presence :

How can we increase the presence of the person in the community?

2. Community Participation:

How can we expand and deepen people's relationships and friendships?

3. Dignity

How can we enhance the reputation people have and increase the number of valued ways people can contribute?

4. Promoting Choice

How can we help people have more control and choice in life?

5. Supporting Contribution:

How can we assist people to develop more competencies?

### **3.4 Student Development**

Developing the behavioral quality of self-determination is the foundational key to success (Field, et al., 2003; Hellendoorn & Ruijssenaars, 2000). From research literature, an effective method for developing self-confidence involves five steps(Field & Hoffman, 1996 cited in Kohler, P. D. & Field, S., 2003). They are :

1. Know Yourself
2. Value Yourself
3. Plan
4. Act
5. Experience Outcome and Learn

For development of live-long learning, ten adaptive skill areas (Luckasson & Spitalnik, 1994 ) can be used as curriculum focus as below:

1. Communication
2. Self-care
3. Home living
4. Social skills
5. Community use
6. Self-direction
7. Health and safety
8. Functional academics
9. Leisure
10. Work

### **3.5 *Interagency and interdisciplinary collaboration***

There is a need to work closely with community businesses(e.g. NTUC), organizations(e.g. NCSS, MCYS) and agencies(e.g. MOM, VWO, MOE) in all aspects of transition-focused education so that mutual needs can be discovered. With fostering by interagency agreements that clearly articulate roles, responsibilities, communication strategies, and other collaborative actions , an enhanced curriculum(e.g. job skills) and program development(job development and training) and service delivery(e.g. coordinated supply and line of work) could be developed (Benz, Lindstrom, & Halpern, 1995; Blalock, 1996; Kohler 1996, 1998 cited in Kohler & Field, 2003). A holistic program necessitates the implementation of an integrated system that addresses lifelong learning and support needs and not terminating at immediate needs of employment. Interagency collaboration and support for individual students in transition and their families are critical factors for continual success (Devlieger and Tech, 1999 cited in Kohler, P. D. & Field, S., 2003)). For facilitation, the community transition team model should be considered for learning how to build school and community capacity to better serve students' transition service needs (Benz, et al.,1995).

### **3.6 *Family Involvement***

Family involvement is critical for the success on transition, as they play a pivotal roles, in creating a nurturing environment, that builds up the child's self-esteem and confidence, a key component in self-determination and also their vision for the future(Morningstar, et al., 1995; Blackorby & Wagner, 1996; Flaxman & Inger, 1991;- all cited in Kohler & Field, 2003). Moreover, strong and continuous family and educators collaboration in direct, routine communication strategies, such as face-to-face conference, telephone contacts, open house events, teacher notes, and classroom visits, improved educator and family interactions, will result in further implied improvements in school attendance, assessment scores and reduce drop out rates(Newman & Cameto, 1993 cited in Kohler & Field, 2003).

Perhaps, we should move towards collaboration with a central governmental body, for building a comprehensive and meaningful long term Individualized Education Plan(IEP) transition goals focusing on long-term job placement & employment outcomes, using personal future planning strategies(Hutchins & Renzlia, 1998; Flannery et al., 2000 - cited in Kohler & Field, 2003 ) can be envisaged for long term effectiveness. The clear and foreseeable future would certainly assure parents and also provide a meaningful, holistic and continuous life-long curriculum and effective intervention. This empowering vision would logically engage parents to be highly active participant in equipping their child to be useful and independent citizens of society.

Kohler(1996) cited in Kohler & Field, 2003 , advocated three aspects of family involvement to facilitate for effective transition. They are :

1. Participation and roles in planning and delivering individual- and community-level transition education and services, such as assessment, decision making, policy development, and as trainers.
2. Empowerment strategies that facilitate meaningful family involvement in transition-focused activities, such as specific methods to identify family needs.
3. Family-focused training that increases family members' abilities to work effectively with educators and other service providers and vice versa.

### **3.7 Program Structure**

Program structure refers to the framework to implement transition-focused education. Our VWOs can consider the six characteristics of effective sites, which implemented the Individuals with Disabilities Act(IDEA) transition mandates(Hasazi et al., 1999, p 558 cited in Kohler & Field, 2003). These are :

1. Incorporation of systemwide, student- and family-centred strategies;
2. Fostering of effective and substantive interagency collaboration;
3. Facilitation of systemic professional development;
4. A visionary, supportive, and inclusive set of reform efforts;
5. Coordination of an integrated set of reform efforts; and
6. Emergence of connections among a variety of local and federal transition initiatives

### **3.8 Paradigm Shift Initiators (Luckasson & Spitalnik, 1994)**

Having “know-how” without effective action becomes NATO (No Action Talk Only) outcome. The paradigm shift initiators needs to be identified and from these to identify the point of greatest leverage to act on. Basis for such approach is from system thinking paradigm which advocates that if the point of greatest leverage can be identified, then action at this point, will produce the greatest effectiveness towards the goal. There are three paradigm shift initiators identified from the US experience (Luckasson & Spitalnik, 1994). They are :

1. Interaction of Advocacy (Advocate needs on behalf of people with special needs)
  - a. Parents cum Caregivers (prime movers)
  - b. Media (creating awareness by capturing naturalistic realities of concern areas)
  - c. Political (politicians advocating on behalf of large electoral parental voice for social improvement )

2. Public commitment

a. Legislation & Funding

3. Technology

a. Enablement and empowering technologies (e.g. <http://www.inclusive.co.uk>)

The point of greatest leverage from majority of the readings (Inciong & Quijano, 2004; Deng & Poon-McBrayer, 2004; Gillies & Carrington, 2004; Leong, 2004; Poon-McBrayer, 2004) stems from parents cum caregivers collective action in the electorate, to persuade and convince need for social improvements. A case in point, is the formation of Asian Women's Welfare Association (AWWA) in Singapore, which started from very humble beginnings of two mats, seven children in hall of St Ignatius Church in March 1979, to hall at St James Church with some storage space and eventually to become established and recognised now (Lim & Quah, 2004, pp 37-38).

### **3.9 Tracking**

Implicit in all the research papers and intervention carried out is the continuous monitoring, assessment, appropriate intervention and documentation, which makes it effective. Parents/Caregivers who constantly maintains and shares the information, are able to promote effective intervention programs. My reading shows that tracking only happens when the person with special needs is a member of a VWO/institution/care-group. Universally, there is no central repository by government, tracking all people with special needs from cradle to grave, on their progress in life and need for help. I suppose there is tracking for income tax collection, but not for their special needs.

Personally, I believe a centralized repository of e-Portfolio containing all special needs children and adults documentation of treatment, learning, assessment, intervention, personal and family particulars, current status of person (at least annually), etc, would serve to both track and allow all educators, therapist, medical professional, social workers, etc, to be able to update themselves on the cumulative learning developments and documents of all special needs people.

The significance can be seen from the following:

1. Shortening the time for the VWO to learn all about the child for effective intervention (Easy retrieval of child records by new teacher will allow continuation and better understanding of the child for intervention.)
2. Shortening the time for the child to adjust to new institution (benefit from (1)).

3. Knowledge of the previous skill learnt will allow the next teacher/VWO to continue and not repeat curriculum. This will facilitate building up from existing skills.
4. Gradual build-up of cumulative knowledge of child through the years.
5. Annual update of status of person will ensure that all persons with special needs are tracked and their existing state known from cradle to grave, allowing any need for help detected.
6. Means for VWO to update annually or before transition to different class/VWO, so that records are complete.
7. Potentially, the information can also be used to streamline, co-ordinate and meet the needs of all with special needs by knowledge of the status of each VWO vacancy and matching the child to available places. This will reduce waiting time and allow faster intervention. It's analogous to the joint admission exercise to tertiary institution after O level results are released.
8. Potentially, it is also consolidation of all available services in all VWO, where the updated information allows the public to learn of status of vacancy as well as for hope. VWO can link up with each other and learn from each other.
9. Moreover, it would be easy to obtain accurate statistics for planning needs of all with special needs and also for research efforts to be coordinated and streamlined.

Essentially it will be an online system that will accumulate all information on people with special needs from cradle to grave in their databases.

This can be seen as analogous to MOE requirement of schools to upload all student data (e.g. performance, conduct, testimony, etc) to HQ, whereby the centralization will allow efficient and effective planning of the needs and resources needed in education.

Similarly, it can also be seen as medical records in a centralized location, allowing the patient to receive appropriate follow-up medical care from any doctor as previous medical history is accessible.

I wrote an email to Dr. Wong Meng Ee of NCSS on the above and the self-explanatory reply is as below:

Thank you for your email and very innovative idea.

Just to share how relevant and timely your idea is: NCSS has the Electronic CaseManagement System (ECMS) that would capture the case notes of a client precisely for the reasons you have spelt out.

In addition, I am in the process of building a Developmental Disability Registry to capture the cradle to grave information of clients of persons with developmental disabilities.

This has several broad functions:

- 1. Repository and tracking function.**
- 2. Track clients information, comments or recommendations for historical, present and future reference.**
- 3. Track status and progress of clients through reports and assessments generated with the aggregate information of the database to identify gaps in services.**

The registry and tracking functions will help to capture the actual numbers of autistic children on the waiting list and assist policy makers to plan for services. Hopefully, this will give a more accurate picture of the apparently overwhelmingly enormous waiting list.

As with most administrative systems, the challenge is to get the VWOs to agree, support and participate in the system.

Best wishes,

Meng Ee

### **3.10 Findings**

To move forward requires vision guided by research knowledge and proven practices, which empowers the engineering of pathways to reach the goal. The significant findings to consider seriously are the following :

1. Effective Transition Practices Framework
2. Paradigm Shift Initiators
3. Tracking

To resolve temporal order problem (chicken-egg) and allow point of greatest leverage (System Thinking Approach), I have decided to start from the paradigm shift initiators of parental collective action whom I hope will power the rest into realization of goals.

#### 4 Action Plan

After much deliberation on what is feasible and practicable (in terms of time frame, expenses and logistics), my action plan is described in the table below. Essentially, it is a plan of action of both building awareness and a network of interested and active parents, to jointly workout possible posts-school follow-up desired future and to work with concerted effort towards it.

What	How	Why	Who	When
1. Share with parents on findings on post-school follow-up	Offer to share to parents in <ol style="list-style-type: none"> <li>1. Autism, Resource Centre</li> <li>2. Margaret Drive Special School</li> <li>3. Any Other places</li> </ol>	Identify like-minded parents who would like to investigate and jointly see social improvement	Norman	May - June
2. Build up keefamily website to be updated with the research findings	<ol style="list-style-type: none"> <li>1. Post this paper on the website.</li> <li>2. Conceptualize knowledge map of post-school follow-up and learning's from research literature in a simplified manner for general assimilation. Populate website with information.</li> </ol>	Open asynchronous sharing to new parents and reinforcement of learning to those who have heard the sharing	Norman	April - July
3. Research on role and services available from NCSS and MCYS	<ol style="list-style-type: none"> <li>1. Check websites for all available information and map the information.</li> <li>2. Interview the appropriate personnel to clarify degree of support</li> </ol>	Verified and validated information of services for parents to access to be upload to website.	Norman	Aug – Sep
4. Build-up of community of parents who have the will and desire to drive the social changes needed	<ol style="list-style-type: none"> <li>1. Collective vision building of post-school follow-up for action.</li> <li>2. Desired item : Planning of Conference of Parents by Parents with Special Needs</li> </ol>	United voice and common vision for effective action	Norman	Oct – Dec

## 5 Conclusion

My personal practical knowledge(PPK) has certainly evolved with the learning of the course. It is a humbling experience when I read about “*Adam’s Story: The Peace That Is Not of This World*”, that reveals how shallow my personal spiritual life is compared to Adam’s, who has cerebral palsy. He is able to fully trust God for all his provisions and has true peace within. Regretfully, I have not attained that kind of peace as I am still struggling with thoughts on what will happen to my children’s future. Notably, it is clear in my mind that labels such as disabled, handicapped, retarded, spastic are strongly detested by people with special needs, as it denotes helplessness and uselessness. On the contrary, terms such as people with special needs, with disability or with nuisance are more desirable, as it does not write off the whole person as disabled. Perhaps, there can be some social improvements in terms of naming. The clarity of the message that people with special needs are every bit a human, with needs like everyone of us, comes out clearly through the learning experiences of the course. Fundamentally, they are humans that have to live with some nuisance that they are stuck with, from birth or via injury or accident. They did not ask for it but have to live with it. We should thus not be patronizing in our encounters and public education is need in this aspect. Moreover, only providing basic needs of food, medicine or shelter for living is not good enough, as in institutional type of help, as their total needs should be considered. They also have the rights to live a meaningful life.

I would like to commend Dr Levan Lim pedagogy used in the course as it has certainly changed the cohort PPK on special education, working on “heartware” rather than “hardware”(i.e. head knowledge). The learning experiences have deep seated impact on our psyche, with achievement of deep and meaningful learning of special education. Perhaps, it is the constructivist approach of providing diverse learning experiences and the subsequent encouragement of personal reflection that makes the course enjoyable and meaningful.

Finally, it is a process, a marathon and also a relay to see to the social improvements of people with special needs, where each generation is needed will fuel the brightness of the light of hope. We are all part of the provision for people with special needs and will all need to do our part to make a difference in their lives and our lives too! May God Bless all who are part of the journey, with our very special group of brothers and sisters, who are evidently more spiritually gifted than us normal people.

## 6 REFERENCES:

- Benz, M. R., Linstrom, L. E. & Halpern, A. S. (1995). Mobilizing local communities to improve transition services. *Career Development for Exceptional Individuals*, 18, pp 21-32.
- Blackorby, J., & Wagner, M. (1996). Longitudinal postschool outcomes of youth with disabilities: Findings from the National Longitudinal Transition Study. *Exceptional Children*, 62, 399-413.
- Blalock, G. (1996). Community transition teams as the foundation for services for youth with disabilities. *Journal of Learning Disabilities*, 29, pp 148-159.
- Blue-Banning, M., Turnbull, A. P., & Pereira, L. (2002). Hispanic youth/young adults with disabilities: Parents' visions for the future. *Research & Practice for Persons with Severe Disabilities*, 27, 204-219.
- Devlieger, P. & Trach, J. (1999). Mediation as a transition process: The impact on postschool employment outcomes. *Exceptional Children*, 65, pp 507-523
- Field, S. & Hoffman, A. (1996). *Steps to self-determination: A curriculum to help adolescents learn to achieve their goals*. Austin:PRO-ED
- Field, S., Sarver, M. D., & Shaw, S. F. (2003). *Self-determination: A key to success in postsecondary education for students with learning disabilities*. Remedial and Special Education, 24(6), pp 339-349.
- Flannery, B., Newton, S., Horner, R., Slovic, R., Blumberg, R., & Ard, W. K. (2000). The impact of person-centered planning on the content and organisation of individual supports. *Career Development for Exceptional Individuals*, 23, 123-137
- Flaxman, E., & Inger, M. (1991). Parents and schooling in the 1990s. *The ERIC Review*, 1(3), 2-6
- Gartner, A., Lipsky, D. K., & Turnbull, A. P. (1991). Culture and disability. In A. Gartner, D. K. Lipsky, & A. P. Turnbull (Eds.), *Supporting families with a child with a disability: An international outlook* (pp. 17-56). Baltimore: Paul H. Brookes.
- Gillies, R. M. & Carrington, S. (2004). Inclusion: Culture, Policy and Practice: A Queensland Perspective. *Asia Pacific Journal of Education*, 24(2), September 2004, pp 117-128
- Greenspan, S. I. & Weider, S. (1998). *The CHILD with SPECIAL NEEDS: Encouraging Intellectual and Emotional Growth*. Persus Publishing.
- Groce, N. E. (1985). *Everyone here spoke sign language: Hereditary deafness on Martha's Vineyard*. Cambridge, MA: Harvard University Press.
- Hannaford, C. (1995). *Smart Moves. Why Learning Is Not All In Your Head*. Great Ocean Publishers.

- Harlan-Simmons, J. E., Holtz, P., Todd, J., & Mooney, M. F. (2001). Building social relationships through valued roles: Three older adults and the community membership project. *Mental Retardation*, 39, 171-180.
- Hasazi, S. B., Furney, K. S., & DeStefano, L. (1999). Implementing the IDEA transition mandates. *Exceptional Children*. 65, pp 555-566.
- Hellendoorn, J., & Ruijssenaars, W. (2000). Personal experiences and adjustment of Dutch adults with dyslexia. *Remedial & Special Education*, 21, 227-239.
- Hutchins, M. P., & Renzaglia, A. (1998). Interviewing families for effective transition to employment. *Teaching Exceptional Children*, 30(4), 72-78.
- Inciong, T. G. & Quijano, Y. S. (2004). Inclusion of Children with Disabilities: The Philippines Experience. *Asia Pacific Journal of Education*. 24(2), September 2004, pp 173-191.
- Karuth, D. (1985). If I were a car, I'd be a lemon. In A. Brightman(Ed.), *Ordinary moments: The disabled experience*(pp. 9-31). Syracuse, NY: Human Policy Press.
- Kranowitz, C. S. (1998). *The Out-of-Sync Child. Recognising and Coping with Sensory Integration Dysfunction*. The Berkley Publishing Group.
- Kohler, P. D. (1996). *Taxonomy for transition programming: Linking research and practice*. Champaign: University of Illinois at Urbana-Champaign, Transition Research Institute.
- Kohler, P. D. (1998). Implementing a transition perspective of education: A comprehensive approach to planning and delivering secondary education and transition services. In F. R. Rusch & J. Chadsey (Eds.), *High school and beyond: Transition from school to work* (pp 179-205). Belmont, CA: Wadsworth.
- Kohler, P. D., & Field, S. (2003). Transition-focused education: Foundations for the future. *Journal of Special Education*, 37, 174-183.
- Leong, K. T. (2004). Inclusive Education in Brunei Darussalam. *Asia Pacific Journal of Education*. 24(2), September 2004, pp 129-142
- Lim, L. (1998). Person-Centred Planning for Pupils At-Risk. *REACT*. June 1998
- Lim, L., & Choo, L. H. (2002). Disability and education in Singapore: What are our implicit theories? In A. G. Tan & L. C. Law (Eds.), *Psychology in contexts: A perspective from the South East Asian societies* (pp. 145-163). Singapore: Lingzi Media Pte Ltd.
- Lim, L., & Quah, M. M. (Eds.) (2004). *Educating learners with diverse abilities*. Singapore: McGraw-Hill.

- Lim, L., & Quah, M. M. (2004). Foresight via hindsight: Prospects and lessons for inclusion in Singapore. *Asia-Pacific Journal of Education*, 24, 193-204.
- Lim, L., & Nomanbhoy, D. (1998). Are we visionary in our service planning? *Integrator*, 8, 16-19
- Luckasson, R., & Spitalnik, D. (1994). Political and programmatic shifts of the 1992 AAMR definition of mental retardation. In V. J. Bradley, J. W. Ashbaugh, & B. C. Blaney Eds.), *Creating individual supports for people with developmental disabilities*. Baltimore: Paul H. Brookes
- Maurice, C, Green, G. & Luce, S.C. (1996) *Behavioural Intervention for Young Children with Autism. A Manual for Parents and Professionals*. Pro-Ed Inc.
- Mesibov, G. & Howley, M.,(2003). *Accessing the Curriculum for Pupils with Autism Spectrum Disorders. Using TEACCH Programme to Help Inclusion*. David Fulton Publishers.
- Morningstar, M.,Turnbull, A., & Turnbull, H. R. (1995). What do students with disabilities tell us about the importance of family involvement in the transition from school to adult life? *Exceptional Children*, 62, 249-260.
- Newman, L., & Cameto, R. (1993). *What makes a difference? Factors related to postsecondary school attendance for young people with disabilities*. Menlo Park, CA: SRI International.
- O'Brien, P. (2003). Envisioning the future without the social alienation of difference. *International Journal of Disability, Development and Education*, 50(1), 17-38.
- Poon-McBrayer, K. F. (2004). Equity, Elitism, Marketisation: Inclusive Education in Hong Kong. *Asia Pacific Journal of Education*. 24(2), September 2004, pp 157-172
- Pottie, C., & Sumarah, J. (2004). Friendships between persons with and without developmental disabilities. *Mental Retardation*, 42, 55-66.
- Sumarah, J. (1987). L'arche: Philosophy and ideology. *Mental Retardation*, 25, 165-169.
- Saxton, M. (1985). The something that happened before I was born. In A. Brightman(Ed.), *Ordinary moments: The disabled experience*(pp. 127-140). Syracuse, NY: Human Policy Press.
- Tabatabainia, M. M. (2003). Listening to families' views regarding institutionalization and deinstitutionalization. *Journal of Intellectual & Developmental Disability*, 28, 241-259.
- UNESCO. (1994). *The Salamanca Statement & Framework for Action in Special Needs Education*. World Conference on Special Needs Education: Access and Equality. New York: UNESCO.
- Whitney-Thomas, J. & Hanley-Maxwell, C. (1996). Packing the parachute: Parents' experiences as their children prepare to leave high school. *Exceptional Children*, 63, 75-87.

Wong K.M. (2004). Amazing Grace. *The Straits Times*. Jan 18, 2004

Young, L., (2003). Residential and lifestyle changes for adults with an intellectual disability in Queensland 1960-2001. *International Journal of Disability, Development and Education*, 50, 93-106.