

**DEVELOPING A SEAMLESS TRANSITION PROCESS**

**FROM SCHOOL TO ADULT LIFE EXPERIENCE**

**FOR STUDENTS WITH**

**VERY HIGH AND COMPLEX NEEDS**

**“Treat people as learners and you treat them with respect.  
Treat them as ‘cared for’ and they risk becoming devalued.”**

John Buckingham, 2011

**Faye Philp**

**Sabbatical Report**

**Term 3, 2011**

# CONTENTS

<b>SECTION ONE</b>	<b>Introduction and rationale</b>	<b>2</b>
<b>SECTION TWO</b>	<b>A case in point, the problem</b>	<b>4</b>
<b>SECTION THREE</b>	<b>Quality of life</b>	<b>6</b>
<b>SECTION FOUR</b>	<b>Service delivery gap</b>	<b>8</b>
<b>SECTION FIVE</b>	<b>International literature search</b>	<b>10</b>
<b>SECTION SIX</b>	<b>Evidence of Need</b>	<b>17</b>
<b>SECTION SEVEN</b>	<b>A collaborative partnership model</b>	<b>18</b>
<b>SECTION EIGHT</b>	<b>Preparing for the uncharted future</b>	<b>22</b>
<b>SECTION NINE</b>	<b>Summary</b>	<b>22</b>
<b>SECTION TEN</b>	<b>Next steps for Carlson School</b>	<b>23</b>
<b>APPENDIX 1</b>		

## **SECTION ONE**

### **SPECIAL NOTE**

This report is written with particular regard to the students and families of Carlson School for students with Cerebral Palsy. Epsom, Auckland.

[www.carlson.school.nz](http://www.carlson.school.nz)

### **ACKNOWLEDGEMENTS**

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- The senior management team and office administrators who kept everything rolling smoothly in my absence.
- J.P. for her professional alliance

### **INTRODUCTION**

Transition signals a change, a defining stage in evolution. A smooth transition is efficient and allows a process to flow with minimal barriers to fulfillment. This report explores the needs of young people with Very High and Complex Needs (V.H.C.N.) and their families at the time of moving on from school. The English term P.M.L.D. (profound and multiple learning difficulties) is also used interchangeably throughout this document.

### **RATIONALE**

Carlson School has a new echelon of students. They are young people who have very high and complex needs and are virtually totally dependent on others for mobility, feeding, drinking, personal cares and communication. They have risen up through the years of schooling at Carlson from 5 years old and are now well into their teen years. Some are nearing 21 when they must leave school. They are young people, who, fifteen years ago may not have survived the neo natal unit in hospital or would have been

resident in Mangere Psychopedic Hospital and would not have attended school. Typically their lives would not extend beyond their teenage years.

Medical, surgical and nutritional advancements made available to these young people means that they are enjoying longer and better quality of life, as are their younger school mates. It is time to recognise that because of the interventions previously noted, a growing cohort of young people are nearing the end of their schooling in numbers unseen before. The end of their time at school flags the cessation of the educational, therapeutic, social and pastoral input and the deep and wide reaching support that the students and their families have enjoyed for the past 17 years.

## **SECTION TWO**

### **A CASE IN POINT, SIMON JONES**

It is December 2010. Simon Jones turned 21 years of age in August. His family brought in food, drinks and decorations for the party held at school on Simon's birthday. Several people made speeches of congratulations and acknowledged that Simon had been at this school for sixteen years, since he was 5 years old.

Simon has profound and multiple learning difficulties (P.M.L.D.) and he is severely affected by cerebral palsy. He is unable to support his own weight when standing and is working towards bringing his right hand to the "mid-line". He uses his eyes to respond (up for yes, down for no) and can, with some physical support, operate an adapted augmentative communication system to make simple statements or ask questions which are programmed into the technology. Simon needs considerable time to process, organize then implement any actions. He has no ability to communicate verbally.

Simon is reliant on others to feed him food of a particular consistency, and to take care of his personal needs. For much of his day Simon sits in his custom built wheelchair. To move him in or out requires two people to manoeuvre him into a sling and move him by hoist to an alternative placement.

Simon's family has expressed their anxiety about the future placement for him beyond school, comments such as 'We just imagined that he would always be at Carlson. That's where all his friends are and everyone knows and likes him.' "If there is no place

for him to go every day, I will have to give up my job to look after him". are typical of the families of Simon's peers

After visiting adult respite /supported living service, his mother said to me "Simon is our 'little boy'. We can't think of him being in a place where there are only adults. How will they know what makes him happy."

Simon is representative of an emerging population of young people with Very High and Complex Needs who are now graduating from (Special) schools.

NB 'Simon' is fictitious and yet typical

## **THE PROBLEM**

The number of children being born with Cerebral Palsy (CP) has remained relatively constant over many years (2 per 1,000 live births). The number of children born with CP and surviving to adult hood has increased steadily in line with advances in medical, pharmacological and surgical management of the sequelae resulting from this condition.

There has been a dramatic increase in population in Auckland specifically in the west and within the South Eastern Corridor. It follows then that there will also be an exponential increase in the numbers of students with Very High ORS needs over time.

All of the above have resulted in an increased demand for "life after school" services for these clients and their families in Auckland. The increased number of senior students with CP enrolled at school until they are 21 years of age has not been offset by a decrease in the number of young students with CP accessing school in the junior school, thereby putting strain on the current school resources.

The transition process from school to "life after school" is extremely stressful for the student and family alike. The school is likely to be one of the few familiar and trusted services that the student and their family have interfaced with for at least 16 years.

## SECTION THREE

### QUALITY OF LIFE

All humans have the same basic biological needs. To survive they need food, water, shelter and sleep. Having one's safety needs met minimizes stress and anxiety and allows an individual to accommodate the activities of daily life, whatever these may be. Belonging is about inclusion; having a family and community network of those who care for and about you and having a peer group of friends with whom you feel comfortable and accepted for who you are. According to Maslow (1947) each level of human need must be accomplished before the next one can be achieved. Thus to have positive self-esteem one needs to have the three previous needs met. Self-esteem arises from valid acknowledgement from those whom we know, like and trust. Finally to reach a stage of self-actualization we need to be able to grow as an individual and be fulfilled in one's daily life.

### Maslow's Hierarchy of Needs

**Self-actualization** (personal growth, fulfillment)

**Self-esteem** (recognition, achievement)

**Belonging** (relationships, meaningful activity)

**Safety** (stability, order, protection)

**Biological needs** (food, shelter, sleep)

Maslow's model' represents the issue of the need for developing a seamless transition between school and life beyond school providers, most appropriately. Research shows that life beyond school for persons with disabilities can slip very quickly from self-actualization down to the point of the first level of basic biological needs only. In the absence of the daily routine (preparing for and attending school and the regular programmes and personnel who are present), the quality of a student's relationships and participatory activities are significantly lowered in their daily life. Self-esteem takes a fall in the absence of recognition for participation and success in structured

programmes and life activities. Continuity of meeting an individual's needs at their optimal level is the essence of the smooth transition.

To ascertain the framework of needs for a young person with Very High and Complex Needs, these questions must be answered specifically for each individual young person.

What do they enjoy?      What do they dislike?      Who are their friends?

What makes them comfortable/uncomfortable?      How do we know?

What are their regular therapeutic needs?      How do they communicate?

What causes anxiety?      What does that look like?      What calms them?

What sights, sounds, textures and smells gain their interest?

At what level are these stimuli appropriate?      What does laughing indicate?

Who will prepare, administer and manage nutrition?      What does nutrition comprise?

Who will prepare, administer and manage medication?      Is this daily or with nutrition?

What medical emergencies may occur?      How shall we know?

How do we keep them safe and well and monitor body temperature?

What is social behaviour for them?      Why do they make loud noises?

What will they do each day?      Who will be a friend?      Who will be a coach?

What links them with family and whanau?      What are their cultural norms?

What technology is significant?      How is it used?

How do we engage them in their world- through experiential sensory activities?

Through community visits or sharing news; personal, local, national global?

Who decides what will their goals be?      Who will give them meaningful feedback?      How?

The mainstream adult population having one's needs met is self-directed and easily communicated. Individuals can express themselves and act in response to need. For students with PMLD their needs are relative, but their means of communicating those needs are severely compromised.

**The presence or absence of knowledge relating to these individual's needs, impacts on their quality of life.**

**It is a societal indicator of respect for the life of an individual.**

## **SECTION FOUR**

### **THE SERVICE DELIVERY GAP**

"Life after school" for young people with very high and complex needs is an area of need which is being poorly met in this country.

These students are at school until they turn 21 and the decision to find a post school option is regularly too disturbing for many families to face. Up until that time their main support experience has been via the school and there are very few post-school programme providers who can offer total solutions for young people with PMLD and their families. Traditionally many students and families fall through the cracks upon leaving school. The student often becomes isolated at home and the family must assume all responsibility for that young person's care and support, often placing untenable stress on the family unit. Evidence suggests that this in turn is often the catalyst for the breakdown of family dynamics which can lead to those young people not being able to remain in a family unit. It is also known that other family members of school age become poor attenders so that they can be at home and provide support to the young person with VHCN. Some young people are domiciled to aged care facilities, which deny a young person "the right to a valued social role within their community".

There are very few appropriate "life after school" programmes available for this vulnerable group. The Student Transition Service set up by the Ministry of Social Development (designed to coordinate this transition period) has only been available over the recent years. This service is useful for students with special needs who are likely to continue their education or gain work skills for future supported employment.

This is not the case for these students with VHCN. There are there are;

1. limited organisations who provide suitable programmes in accessible environments (wheelchair access and bathrooms)
2. even fewer organisations who run an all-day programme
3. Low levels of government funding which means minimal resources (staffing and equipment) available to support the programmes.
4. additional high costs associated with suitable transport to and from the programme often precluding regular daily attendance



Thus a transition coordinator' support has limited value to these students and their families because there are so few options available if parents choose to continue their own employment.

These barriers seamless transition to life beyond school have become obvious over the last year, for the first time senior students at Carlson School have reached 21 years of age.

The literature search that follows illustrates a common theme, that this is a worldwide phenomenon and significant social challenge.

## **SECTION FIVE**

### **Literature**

#### **FROM AUSTRALIA**

The significance of effective hand over between health professionals and the individual's medical information appears in two articles published by Novita Children's Health Services in Australia. Reviewed on 17<sup>th</sup> November 2008

"The move to adulthood is an important milestone for young people with a physical disability and their carers. It can be a time of anxiety if it is not clear how services are going to be provided... When planning a smooth and successful move from Novita children's services to adult services Novita lists a range of contacts regarding; medical equipment, day programmes, accommodation services (respite and residential), therapy services, family support services, funding streams and resources" Novita, 2008.

The same organisation notes;

"When parents have a child with a disability they usually find themselves needing to make relationships with a wide range of professionals. This usually continues for many years. However changes of professionals are unavoidable... Novita recognises that "the relationships between the parents and the professionals are very important and highly valued." Novita, 2008

At the critical time when young people with PMLD are transitioning from child to adult services the young person, their family and the health professionals/ agencies/school need to transfer essential information very carefully to ensure continuity of health and

safety for the young person. Personally I have knowledge of a potentially life threatening situation that recently arose when a student aged twenty was admitted to hospital adult services for the first time. Whilst the patient was 20 years old she was the body size of a ten year old and suitably sized equipment was not to hand at the time of acute need.

Many children who have PMLD have a diagnosis of Cerebral Palsy (C.P.) CP is the most common physical disability in childhood. Over 33,000 Australians are estimated to have CP. Increasing numbers of young adults are transitioning to adult services from coordinated multidisciplinary pediatric hospital services.

On a progressive note Barbara Field visiting medical officer at Westmead Hospital Sydney writes;

“Over the past 2 decades interventions such as botulinum toxin –A, intrathecal baclofen infusion, gastrostomy feeding and single event multilevel orthopedic surgery have improved the lives of many children with CP. These interventions are generally delivered within multidisciplinary rehabilitation programmes in pediatric hospitals. As the most recent cohorts of children move into adulthood their carers have expectations of similarly structured services in the adult health care sector. The Children’s Hospital at Westmead and Westmead Hospital recognised this need and developed a multidisciplinary consultative clinic for adults with CP..... against the tide of limited funding, lack of trained staff and fragmented medical surgical and allied health teams”.

In other words interventions from medical science are improving the quality and length of children with CP/PLMD’s lives. However it is increasingly apparent that this ‘emergent’ population of young people is not catered for adequately as they transition to adult services (or the lack of those services).”

Barbara Field goes on to advise that, “The Westmead Hospital Adult Physical Disability Centre has set up clinics for young adults with CP transitioning from pediatric services, a more clearly defined pathway and access to specialist assessments and interventions. They will insure that these teams include therapists, social worker, psychologists and nurse coordinator. Funding for orthotics and equipment such as walking aides and wheelchairs is also essential.” March 2010

## **ASSISTANCE IN QUEENSLAND**

Literature from Queensland Australia (2010) under the heading "Support for school leavers" information promulgated by the Department of Communities, Disability and Community Care Services has a range of services and supports which are available to assist Queenslanders with a disability. Disability and Community Care Services connects people with funded service providers that can "help them set and realize their goals". A person who has a substantial reduction of capacity in communication, social interaction, learning, mobility or self-care management can apply for assistance. Needs assessor will ascertain the level and nature of support required. The package will be framed around 1:1 staffing to assist with a plan for the future and access to services beyond school. The information states, "School leavers from 2011 will experience clearer more efficient, responsive and more effective supports that meet their needs."

## **AUSTRALIAN SPECIAL EDUCATION LEADERS.**

The Australian Special Education Principals Association (ASEPA) promotes research and professional development for persons and organisations who make decisions that affect those children who have special educational needs.

"There is a commonly held misconception that advances in technology and medical science have led to a decrease in disabling conditions. International research does not support this view. There is actually strong evidence to suggest the nature of disability is changing, resulting in an increase in some disabling conditions". Examples of these are Foetal alcohol syndrome, IVF programmes resulting in multiple births and pre term babies, non-accidental injuries or poor ante natal health.

Special schools and indeed mainstream schools are finding that they have children enrolling in facilities that lack pedagogical knowledge to teach these children. Nor are they adequately or appropriately staffed, nor physically designed to accommodate students with Very High and Complex Needs. ASEPA (2009)

If this is the impact on schools then it begs the question what lies beyond school for these youngsters?

## **POST SCHOOL OPTIONS –ADULTS WITH HIGH SUPPORT NEEDS.**

The Australian Special Education Principals research also documents, “There is a need for the development of a wide range of post school option pathways for young adults with high support needs to maximize their potential (in Australian society) . In Australia parents of a child with severe disabilities have the security of knowing that their child is involved in developmental activities 5 days a week for 40 weeks of the year. As the young person reaches school leaving age that security is significantly reduced. Parents need to find a post school provider who can meet their child’s unique needs as well as seek government funding for the young person to attend 5 days per week”. Regularly the funding is insufficient and one parent must give up work to attend to the young person with special needs. In some cases a sibling withdraws from school to be the career”. ASEPA (2009)

This article paints a realistic correlation of how things are for New Zealand families who have a child with Very High and Complex Needs. It is difficult enough to find a placement for their young person and the issue of smoothing the transition has not even arisen at this point!

## **TRANSITION IN THE UNITED KINGDOM.**

In my quest for information regarding transition for students leaving school and moving on to life beyond school, I located websites and/ or ofsted inspection reports of twelve schools in the UK who catered for students with PMLD. I wrote to each of them outlining the current practice here in Auckland together with the Carlson Plan with ‘Centre A’ and asked if they had specific transition plans and partnerships with provider of post school programmes.

I received two short responses which indicated that a process of referral, rather than transition occurred. A third response was more valuable.

*Sadly we find ourselves in a very similar situation to yourselves with our PMLD young people.....they can stay on at Wren until the year in which they are 19, then there is a danger that they could fall into a “black hole” of lack of appropriate facilities and / activities / funding. The social and health care sectors are meant to be working together to plan in advance for those with complex needs to endure there are services to meet*

*need, however, constant local and national political changes have meant that although the theory of person centred planning is sound, in practice there is simply not the physical or financial resources to ensure equity of entitlement, and many young people end up staying at home and becoming isolated socially.....in our experience families of those with complex needs become very tired and run down by the time their son/daughter has reached the end of their teenage years.*

*As a school we have been increasingly concerned about the lack of options for our leavers. We advocate the use of person centred plans for our young people, and prepare personal "passports" that hold the critical information about what is important to and for the young person and we work particularly hard to ensure the most effective communication systems are available for them to use. There are many determined, experienced people working in the 14 to 25 sector in social care and health and education, who are desperately trying to provide better services but in the end it comes down to a lack of funding. Many private companies are setting up now locally, offering support for families in the home or in supporting people with complex needs to have their own home, usually share with one or two others with similar needs.....sometimes this can work really well, but not always, for a whole host of reasons.*

*Faye I think (what you are planning to do), running the school's unit alongside the adult provision is an example of excellent practice, ensuring information is shared, your young people have a gradual and carefully managed transition, and staff learn from each other and develop..... good communication is the key, for our young people and us as practitioners*

*Debbie Withers .Head teacher of Wren Spinney School UK (January 2012)*

*In October 2011 I attended a week of professional development presented by INet School Association at Warwick University. During the course of the week we visited four Special Schools which catered for students with a range of needs. It was quite apparent that schools took responsibility for students until such time as they left school. The post school options were run by Trusts and were quite separate from schools. I saw no evidence of dovetailing or handover arrangements. Having said that, the majority of students that I met were more likely to go on to supported learning or employment.*

## **MILTON KEYNES (SPECIAL EDUCATION) INCLUSION STRATEGY 2009-2011 (UK)**

This comprehensive data rich 60 page document carried the following themes to support children with special needs and their families.

- Develop a continuum of provision for children and young adults.
- Improve continuity of pathways particularly through transition.
- Build partnerships with families, children and a range of agencies and providers
- Ensure the highest quality leadership and management to support vulnerable children.

These themes are common in the Australian, British and New Zealand rhetoric. However, resources need to be available to follow through on the intentions.

### **A BRITISH COMMENT**

John Buckingham writes about the rights of those with special needs to be regarded as learners. His view links with the writings from SEPA about giving the students who require it an extended opportunity to be lifelong learners with the support and regard that is appropriate.

“For most people leaving school means an end to (formal) learning, increased independence and the freedom to make one’s own successes and mistakes. For people with PMLD this transition is rather different. If people are delayed in their communication skills does that mean we allow them the standard 14 years of education? (UK System) Surely we keep teaching communication until we feel we’ve reached a natural limit? Consigning people with delayed development to being merely cared for not taught just because they are beyond school age is inhuman” Buckingham challenges facilities which ‘care for’ people with PMLD as extensions of schooling. He recommends that such places are places where those with delayed abilities can continue to learn to their potential. “Learning is a lifelong process for us all, even more so for those of us who learn less quickly and need extra help.” J Buckingham (2010)

This supports the argument for the provision of facilities which are geared to the needs of those with Very High and Complex Needs. Through dovetailed transition, this can be achieved.

## **COLLABORATIVE PARTNERSHIPS IN ENGLAND**

“The high quality education to which our children are entitled is very staff intensive and requires continuous collaboration between lots of professionals. When children’s services and primary care trusts work in partnership and put in the resources, the children with PMLD really benefit “

Cathy Welsh. Head teacher at Jack Tizard Special School, London. 2010.

From (parent) Jake Foreman’s perspective

“People with no experience of children with profound and multiple disabilities may wonder if it’s all worth it. From a parent’s point of view anything that can be done to enhance my daughter’s happiness and skills is very important”. J. Foreman (2011)

This parent values the opportunity for his daughter to stay on at her current special school until she is 25. This means she can continue to benefit as she moves into adulthood. However a comment from another English Special School principal rings true, “The sad thing that for most people with P.M.L.D is that when they get to 19 the funding stops and they get put into residential homes which rarely embrace education”.

Jan Cunningham, Principal of St Margaret’s Special School. (2011)

## **FROM NEW ZEALAND**

The New Zealand Ministry of Education has recently published a fourteen page document “Preparing to Leave School” Information for parents and caregivers of young people with special education needs. There is reference to housing options, moving into tertiary education, moving into employment and help with advocacy and budgeting. There is no reference to those young people who are transitioning from school for whom tertiary education or employment are not options. What does this reflect in terms of our Government’s recognition and preparedness for this emerging population of young people with PMLD?

Typically a Very High ORS funded student can use ORS funding as they move on from school. During the final year of schooling the student and his/her family has access to an independent transition coordinator. This is a useful concept. However the reality for our students is that there are very few organisations that run full day programmes for those young people with PMLD, most have waiting lists, and there is limited funding to

enable travel from home each day to the site of the programme. The significance of a full day programme means that the family routines and employment can continue as it was when the student was at school. Opting for sessional activities means that a family member or carer must be available to take responsibility for the young person whilst the other family members are at work.

## SECTION SIX

### EVIDENCE OF NEED

Students with Very High and Complex Needs turning 21 and due to leave Carlson School for students with cerebral palsy, by year.

Prior to 2009	0	2010	1	2011	2	2012	4
2013	3	2014	3	2015	3	2016	4
2017	7	2018	2	2019	4		

These numbers of students with V.H.C.N. show that up until 2009 no students at Carlson School remained on the roll until they were 21. In 2010 one student graduated, in 2011 two more students will need meaningful day programmes .Over 10 years 33 students are likely to need careful and smooth transition to adult life experience. There is of course a spread of students with similar needs across Auckland. Their numbers will likely treble the total group. There will be similar numbers of young people with VHCH across NZ for whom school years are ending. The sixteen years of educational, therapeutic and social integration, the resources of trained and support people, equipment, and medical intervention and comes to an abrupt halt at the end of the year that the young person turns twenty one. What then?

The following model offers a solution.



## **SECTION SEVEN**

### **A COLLABORATIVE PARTNERSHIP MODEL**

This innovation of developing a transition model bridging school and adult life after school, is based on the knowledge that the transition from school to a programme post school for the Very High Need, O.R.S.S funded students is extremely stressful for both the student and their family/whanau and that a smooth transition can have benefits for all concerned.

Since 2009 Carlson School and Centre "A" (which operates a day programme for young adults with Very High Needs) have explored several bridging transition options in terms of programmes and resourcing. Carlson School and Centre "A," share a vision.

We believe that 'our young people will lead as valued, purposeful and independent a life as possible in their communities". A plan to create an environment which enables them to;

- Be happy and treated with respect
- Have the opportunities to make meaningful choices in day to day decision making and with the more fundamental life choices
- Have the opportunity to develop the competencies and skills to be able to undertake functional and meaningful activities
- Have a community presence in all the ordinary places that define community life
- Participate in the social life of the community through involvement in a growing network of personal relationships.

Carlson School believes that a transition class at "A" site could create a bridge to life post school which is supported by a trusted and specialised adult service provider who can provide appropriate solutions and support for the student and their family/whanau throughout the rest of that young person's life (respite, supported living, living skills training, vocation/occupation, health and wellness) in short, "life style and life roles".

The main outcome of this initiative will be a planned, stress free and seamless transition from a school to life after school for students and families.

## **HOW WILL WE ACHIEVE THIS VISION?**

The Carlson School strategic plan goals guide our planning.

- 1) Develop a collaborative process of effective transition for students and their families to apply to a range of needs
- 2) Develop and implement policy and procedure for transition of young adults into the community at the end of their schooling.

## **A WAY FORWARD**

The Carlson/"A" programme model offer a solution in terms of a seamless transition. Catering for those students aged 18-21 has consequences for schools at the 'front end' whilst supporting the "tail". The Carlson/ "A" programme model offer a solution in terms of moving students through the process much more effectively. This excerpt from the proposal document to the Ministry of Education explains;

"The majority of these students will require other services throughout their life time and many of these services can be provided by other "A" specialties. It is highly likely that "A" would be the provider of choice for these services due to the interface already created through the existing programme.

A programme has been designed to build a bridge for the client and family between the school and post school programme which facilitates sharing of knowledge, trust and respect for all parties. This project also involves the implementation of a collaborative programme using resources from Carlson and "A" (staff, equipment, materials, programme tools and buildings. Carlson will make a van available for transport for their students which may also be available for the "A" clients where appropriate. It is anticipated that the pilot service manager will be identified, introduced to the Principal of Carlson School, Faye Philp and briefed as to the model and resources required. Families will be notified of this programme and have opportunities to discuss any issues they are concerned about with both Carlson and "A". Staff from both services will be introduced, briefed on the design model, facilitated to work together and given planning time prior to the beginning of next year. A collaborative agreement will be developed between "A" and Carlson School based on a Memorandum of Understanding".

## **BENEFITS TO STUDENTS AND FAMILIES**

An interface between school and "Life after school" services enables families to build trust with other organisations and in the case of "A" may allow families to explore and access other services along the "A" service delivery continuum e.g. respite, living skill training and long term living options - all of which are critical to facilitation of quality of life outcomes. "A" and Carlson School have an aligned vision for their clients and share corresponding philosophy and values.

## **PROGRAMME DESCRIPTION**

The Student Transition To Youth Life Experience (STYLE) programme is a collaborative collection of school and adult service activities - school curriculum, meaningful activity, community participation, on-going learning, based on individual IEP's and designed to facilitate a seamless transition from school to adult services for all participating students. (Refer to appendix 1) A group Carlson School students aged 18 to 21, who are embarking or have embarked on the transition journey from school to post school services, will interface with clients from the "A" VHN Day programme. This interface is expected to encourage the building of trust, respect and friendships within the groups and their families and thus facilitate a seamless transition from school to post school services.

The programme will require a sharing of resources between both organisations (space, staff, equipment, materials, programme tools) and a parent reference group will be established to facilitate feedback from parents for continuous service development.

Many of the daily sessions will be conducted with the two organisational groups together (e.g. recreational choices, physical activation etc.) in order to promote socialisation and knowledge sharing between staff and participants.

Where it is necessary to conduct sessions separately (e.g. school curriculum requirements) the two organisational groups will retire to separate areas within the building. Carlson School retains responsibility for the provision, implementation and monitoring of all specific MoE requirements. "A" retains responsibility for the provision,

implementation and monitoring of all specific Ministry of Social Development (MSD) requirements.

## **STAFF**

The combined team will comprise-

Carlson School Lead Teacher acting as Carlson School Programme Coordinator

“A” Programme Coordinator

Carlson School teachers, one of which is the Lead Teacher

Teacher Aides

“A” Lifestyle coaches

Carlson School Therapy Team

## **NATIONAL IMPLICATIONS**

Development of a model for this initiative in Auckland may allow roll out of the model to communities New Zealand wide

## **RECOMMENDATION FOR EVALUATION**

A research project to test the outcome could be developed through the link between “A” and Auckland University of Technology.

## **THE CURRENT POSITION REGARDING THIS CONCEPT.**

This project was seeded in 2009 and has undertaken several twists and turns due to strategic plan changes and financial restrictions. No joint venture has been successful to date. However the concept has the continued support of the Deputy Secretary for Education Nick Pole, the Carlson School Board of Trustees and key managers at “A.” Some consultation has occurred with families and this has been positive without exception. At the present time the two organisations have downgraded their transition/ dovetail programme to be held on one site. The viable options at the moment are based around a holiday programme with a combined group. A further action may be structured integration for identified Carlson students to attend activities at “A” on a limited basis.

## SECTION EIGHT

### PREPARING FOR THE UNCHARTED FUTURE

Families need to be thinking and talking about the following matters at individual Transition meetings held with school and family every two years from 15 years of age;

- Their child, at 21 years of age is now an adult in the eyes of the world and more specifically in terms of Government funding.
- Who lives in at home now? What do they do during the day?
- Imagine each of those family members in 10 years' time and ask the same questions.
- What about your child with special needs, what does he or she do now?
- What is important for them to continue in time?
- What programmes are available?
- Where are they located?
- Are they for the whole day or sessional?
- What will it cost get there and home again?
- Is there residential /respite availability and location?
- What agencies can assist with future advocacy and guardianship?
- What changes will need to occur in our family life?
- Are there cultural issues to be considered?

## SECTION NINE

### SUMMARY

Most mainstream school charters state that they want their students to reach their full potential. Special Education is no different. If, when our students turn 21 we merely pass them over to another group of largely untrained staff, how will anyone know how our young people learn, communicate, show preferences and participate and contribute to their world as lifelong learners.

**“Treat people as learners and you treat them with respect.**

**Treat them as ‘cared for’ and they risk becoming devalued.”**

## **SECTION TEN**

### **NEXT STEPS FOR CARLSON**

1. Carlson school transition coordinator will develop a policy and procedure for transitioning students to post school life.
2. Carlson school transition coordinator will work with an independent transition coordinator to create comprehensive list of what is available for our graduating students, to include; physical location, physical access, staffing ratio, programme offered, spaces available, cost, peer group, range of services available, self-care facilities.
3. Continue to work with our School Board of Trustees to address this issue of effective transition.
4. Strengthen liaison with Centre "A" as we move forward to address transition and services for young adults with PMLD.
5. Strengthen links with Wilson Trust
6. Personally represent our school community of students with V.H.C.L.N in a planned working party including representatives from Ministries of Education, Health and Social Development, to address the issue of transition.
7. Collect comprehensive data for future planning that illustrates the numbers and physical location of students with V.H.C.N.
8. Invite the new Minister of Education to our school and present this work to her.
9. Create a time line for action

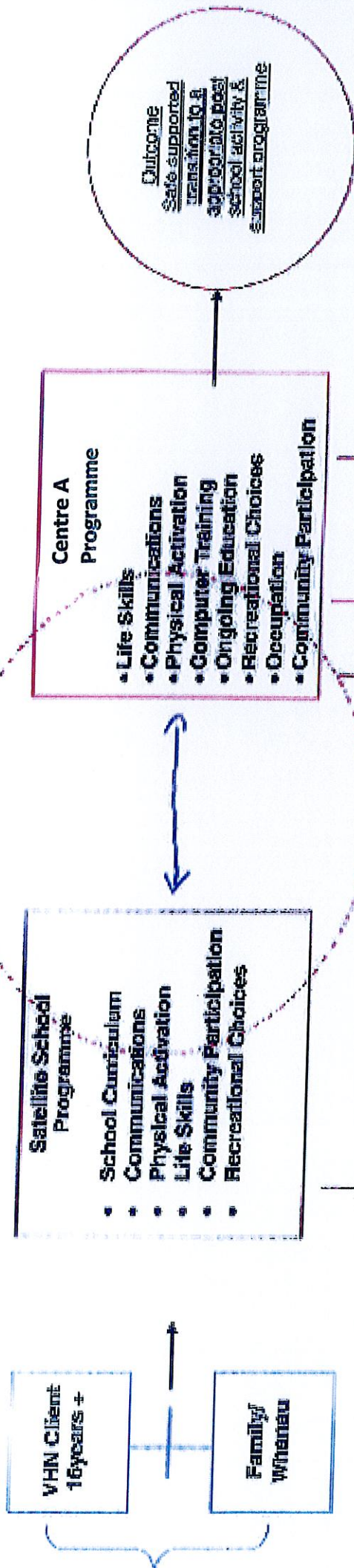
Present this document to;

- Maungakiekie (local) Member of Parliament,
- Ministers of Education, Disabilities and Health Australian
- Special Education Principals' Association,
- New Zealand Special Education Principals' Association,
- INet Special Schools network management (U.K.)

## **APPENDIX 1**

# Out of Home Support – Very High Needs Post School Transition Programme Model

After School Transition Programme (16 – 21 yrs)



- Satellite School Programme**
- School Curriculum
  - Communications
  - Physical Activation
  - Life Skills
  - Community Participation
  - Recreational Choices

- Centre A Programme**
- Life Skills
  - Communications
  - Physical Activation
  - Computer Training
  - Ongoing Education
  - Recreational Choices
  - Occupation
  - Community Participation

**Outcome**  
Safe supported transition to appropriate post school activity & support programme

Student Transition Service (LFR school s/client)

- School to provide**
- Teacher
  - Therapist
  - Equipment
  - Consumables
  - Transport
  - Curriculum

- Centre A to provide**
- Facilities
  - Amenities
  - Teacher Aides
  - Nursing Oversight
  - Student Transition Service
  - Combined Programme

- Centre A to provide**
- Facilities
  - Amenities
  - Rehab Coaches
  - Nursing Oversight
  - LFR Adult Programme

ORS Funding to School

\$80.00 per day per client from School to Centre A

\$80.00 per day per client  
 MSD Funding to Centre A



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- Action for Children, Redwood House, Oxfordshire, UK
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- Hadley Learning Community, UK
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- Hillside Special School, Suffolk, UK
- Kingstanding School, Birmingham, UK
- Meadowgate School, Wisbech, Cambs, UK
- Rose wood School Southampton, UK
- Samuel Pepys School, Cambridgeshire, UK
- Sandside Lodge School, Cumbria, UK
- Severndale School Shrophire. UK
- Southview School Witham, Essex, UK
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- The Clare School, Norfolk, UK
- Treloar Trust, School and College, Hampshire, UK
- Villa Real School, Co. Durham, UK
- William C Harvey School, London, UK
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