

Submission No. 1084

(Inq into better support for carers)

Raylee

ADC 28/7/08

2nd July, 2008

The Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
Canberra ACT 2600

Dear Parliamentary Secretary,

I enclose a copy of my Autistic Son's life's journey since he was 18mths old. This diary has been kept to record my vain attempt to have Luke's syndrome correctly diagnosed and subsequently receive the appropriate therapy.

This journey will never cease due to medical diagnose being non forthcoming for over 27years of his life. The result being he is cognitively impaired, suffering from panic attacks and insecurity in his environment.

We have endeavoured to help Luke be included in society. This support will be needed for the rest of his life.

I have been denied a carer's allowance even though when we completed the application, the form identified that Luke required over 20 hours support from his family per week.

Recently, I heard a representative from your Department state that the Carer's allowance was to help pay for non recoupable medical expenses. This statement contradicts the questions outlined in the Department's application for Carers Allowance Form.

I have two major concerns:-

Acknowledgement of my efforts and caring for my son over the last 39 years and the acceptance of government bodies that Mental Health is as debilitating as physical health and requires as much monitoring and nurturing.

With the realisation of the Autistic Epidemic in our society this barrier has to be withdrawn, otherwise mothers who find themselves in my situation will never receive justice for the burden placed on them for life.

Yours faithfully,

Raylee

Attch. Luke

History and Rejection notice from Social Security

LUKE

HISTORY

AREAS FOR EVALUATION		PARENTAL ACTIVITY	PROFESSIONAL INTERVENTION	OUTCOMES	RECOMMENDATIONS
DIAGNOSES					
1970/1	18mths Minimal brain damage	All known medications were trialled and failed		Unsatisfactory and inconclusive diagnosis until 1997.	On our own
1972			Grosvenor House, Summer Hill NSW 3yrs – Dr. Delacato- Institute for Human Development Philadelphia, USA		
1998	Autistic, Sensory & Auditory Impaired/ Echolalia	Parental awareness of new release on findings of Dr. Aspergers, 1934 and withheld till 1981. Clinical criteria released 1994/5		Too Late!	
TREATMENT/THERAPY					
1972-1975	Sensory and Fine Motor Skills reprogramming	Cross Patterning and Sensory Education on daily basis - 12mths Swimming Lessons – The Junction & Cardiff, Newcastle.		Fine and Gross Motor Skills graded “fair”	On our own
1974			Occupational Therapist consulted at Stockton Mental Hospital for the profoundly retarded. Hospitalised for 3mths, aged 8years in attempt to bowel train him. Sent home on regime of daily enemas – 4yrs.	No benefit	
1977-1981	Bowel Training	Parents administer daily enemas for 4yrs.		Bowel still needs constant attention	

	<p>Psychiatry and Psychological Therapy</p> <p>Speech Therapy</p>		<p>Psychologist & Psychiatrist -2 years 3-5 years of age</p> <p>Speech Therapy Dr. Marcia [redacted], Mater Hospital, Newcastle 3-5 years.</p> <p>Pre-School - 3years Recommended by Speech Therapist. Director had an understanding of special needs children</p>	<p>Little benefit as this exercise was undertaken to classify his learning ability</p> <p>Speech delayed until 7 or 8 years of age. Then very stilted and minimal</p> <p>Tolerance of Luke's behaviour was comforting</p>	
RESPITE CARE	<p>Family in crisis. Unable to take holidays or have quality of life. Elder two children emotionally neglected.</p>	Nil	Nil	Families still in crisis	No respite or social understanding of demands made on family
EDUCATION 1972	Inappropriately graded and entry level of schooling for intellectually delayed children	Requested Early intervention for Luke to be enrolled in OF situation.	<p>Luke was refused early intervention, and classified O.A. (Mildly intellectually disabled) Denied entry to an O.F. Situation (Moderately intellectually disabled).</p> <p>Entry Age 4yrs. Education Dept, Scott Street, Newcastle, classified him as suitable for O.A. situation which did not commence till the pupil</p>	Early Intervention is recognised to be imperative to maximise child's possible development	Opportunity for Luke's maximum development is lost and there is now no route back.

<p>February, 1975</p>		<p>Enrolled him in public education - 5yrs 9mths knowing Australian Constitution requires children over the age of 6yrs to educated.</p> <p>Discrimination.</p> <p>This offer was refused, claiming that it was less than my duty as a mother to accept this limited schooling, as it was less than the Education's Dept's duty by offering these limited hours.</p>	<p>turned 8years</p> <p>Called to Principal's office when Luke was 6yrs and 1mth, who offered limited support for 3 hours per week to be taken over two days claiming Luke was unsuitable for normal school environment</p> <p>An "Adjustment" Class was established in a nearby school (Charlestown) with a ratio of 6 people to one teacher and a teacher's aide. This class eventually became a satellite class for Autistic children.</p>		
<p>1977</p>	<p>Enrolled at Roseville Public School in the OA class.</p>	<p>Family transferred from Newcastle to Sydney.</p>	<p>Mother was challenged by the Principal at Roseville Public School (OA situation) as to his behaviour and level of cognitive skills.</p>	<p>Once again it is the mother's fault!</p>	
<p>1978</p>	<p>Private remedial Tuition</p>	<p>Employed reading therapist to assist in Luke's development.</p>	<p>No Assessment was done on admittance to either class, as the original 1972/76 assessment was used; Ignoring that he had been transferred to an Adjustment Class.</p>	<p>Luke gained moderate literacy skills.</p>	
<p>1980</p>					

<p>1981-1988</p>	<p>Luke (12yrs) was enrolled to an OF situation at Cromehurst Special School.</p>		<p>Luke enrolled in OA situation at North Sydney Demonstration School 1978.</p>	<p>Luke is totally ennumerate and has no concept of money.</p>	
<p>TRAINING 1983-1988</p>	<p>Living Skills for independent living</p>	<p>Mother inaugural president Cromehurst Living Skills Programme successfully lobbies NSW Minister for Education (Ron Muloch) for equity in funding to refurbish cottage owned by the Education Department and designated for demolition, to establish living skills programme for intellectually disabled children.</p>	<p>Department of Public Works extends, modifies and refurbishes Cottage to Committee's Architect's specifications.</p> <p>Department of Education provides additional Demountable classroom to be used for "Art and Creative" classes to replace that which was provided within the "old cottage".</p>	<p>Luke coped very well in his first few years of living independently. He regressed severely when support was withdrawn by Chatswood Supported Living, a DADHC funded organisation.</p>	<p>Education should be structured towards child gaining life skills.</p>
<p>WORK/VOCATION 1988-2007</p>	<p>Sheltered Workshops funded by Federal Government</p>	<p>Mother and Father continually called for Luke's Behaviour and he was suspended regularly without pay.</p> <p>Parents informed management that a "Tin shed" work environment</p>	<p>Chatswood Industries 10 years Sunnyfield Industries 11 years.</p> <p>Entry Level of pay 89c per hour.</p>	<p>20 years of very poor management and total lack of understanding of the needs and work environment required of Autistic people.</p> <p>Poor behaviour indicated his dissatisfaction. Was</p>	<p>Behaviour Interventionist should be pivotal to the staff structure of sheltered workshops, given the diversity of disabilities and low standard of supervisors. These supervisors are often people who English is their second language.</p>

		was unsuitable for Luke's Autistic Syndrome.	<p>Luke never received an increase in hourly pay due to his lack of support from a behaviour interventionist.</p> <p>Constantly sent home because of behaviour issues. No Behaviour Interventionist provided by either organisation.</p> <p>Commenced work at House with No Steps, 20th March 2007.</p>	<p>always punished for his repeated cries for help.</p> <p>Luke is now supported by professionals who have allowed him to be the best he can be.</p>	
ACCOMMODATION					
1990	Group Home Burleigh St., Lindfield		Luke shares room with another boy. House is inadequate for clients needs.	Luke assumes supervisory role over other tenants due to his superior living skills.	See attached paper on public housing.
1992	Private Rental Unit, Peckham Ave., Roseville	Parents provide all living room and bedroom furniture for unit.	Luke is moved into a unit with two other strangers by Chatswood Supported Living Management.	Shares with two other intellectually disabled people. This ceases when unit block is demolished.	
1996					
1999	Devonshire St., Chatswood		Luke acquires different flat mate Luke acquires different flat mate	Down Syndrome woman who challenges Luke's need for personal space.	
2006		Advocacy with DADHC		Sight impaired boy adopts superior attitude with Luke,	
					The Need for Cluster housing is paramount.

		identifies Luke's need to live alone.	Various Government Depts help in Luke retaining residence in unit he has occupied for 10years.	who commences his period of living in a hostile house. Luke now lives alone supported by Home Care. Staff are not trained in their approach to autistic people	Luke is lonely and craves company of his peers and or family. He would love and benefit from having an extended friendly group of his peers living nearby.
SUPPORTED LIVING 1990-2007	Supported Living Agency funded by DADHC.	Mother alerts Government Agencies to fraudulent activities of Supported Living Agency – Chatswood Supported Living. Luke was living in a hostile environment, unsupported and financially disadvantaged. Mother commences another intense journey of advocacy for Luke. Constant monitoring of all monies and payment of accounts	On entry into independent living no Skills Assessment was undertaken. Chatswood Supported Living (CSL) who are funded by NSW Govt. to provide support from 1990 to 2005, failed to provide support. Group funding was allocated to CSL to support Luke. This funding was insufficient as identified by Skills Assessment commissioned by DADHC 2005. State Minister DADHC was alerted and assisted in the Brokering of services to another provider. Luke was given a Case Manager to assist his needs due to his neglect over 15yrs.	Luke's standard of living was gravely affected. He was defrauded by approximately \$15,000.00. Settlement was reached and he received \$4,000.00 re-imbusement.	Policies and Procedures should be revised by DADHC and monitored in Audit Process to protect the disabled from negligence and fraudulent behaviour of carers.

<p>HOME CARE</p> <p>2005</p>	<p>Skills Assessment identifies Luke's need for Home Care Assistance.</p>	<p>All support from 1969 to 2005 provided by parents.</p>	<p>2005 Schedule of assisted support was prepared by Home Care. This schedule is still a work in progress, due to Luke's autism and his entrenched behaviours patterns developed through neglect.</p>	<p>Work in progress 2007 Finding suitable carers who Luke accepts into his home is a very slow process.</p>	<p>This service is not portable as per DADHC's guidelines. Once again Luke is kept waiting And only partially supported.</p>
<p>LEISURE ACTIVITIES</p>	<p>NARA (North Area Recreational Assoc.)</p> <p>The Housing Connection Limited Funding.</p>	<p>Parents provide weekend support and social activities for Luke. All work and public holidays spent in care of parents due to no support available.</p> <p>Mother has to transport Luke to most events as Luke does not travel by train as do the other members.</p>	<p>North Shore Recreation Association declined to allow Luke attendance to Camps, Holidays and Weekend sporting activities, due to his Autistic Tendencies and Echolalia outbursts No vacancies exist for sport, leisure or Social activities for men of Luke's age.</p> <p>The Housing Connection is trying to establish Social Club, commencing with a group outing once each month.</p>	<p>Parents are still his main source of social interaction.</p> <p>Luke is lonely and needs company and stimulation from social activities with his pals.</p>	<p>More funding required to appropriate agencies.</p>
<p>BEHAVIOUR SUPPORT</p>	<p>Nil for 37 years</p>	<p>Mother deals with all levels of attack regarding Luke's behaviour.</p>	<p>DADHC provided Behaviour Interventionist 6mths 2006</p>	<p>Marked improvement in Luke's sense of self</p>	<p>Needs to be more accessible and readily available.</p>