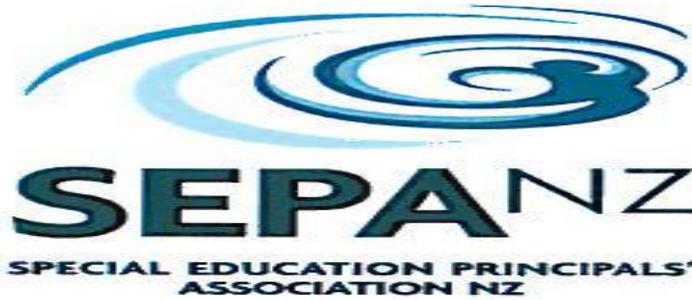


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“It’s not where, it’s how”  
“Ehara I te wāhi ko te tino take, engari me pēhea”

**SEPANz Executive:**

**Northern/Auckland:** [Sally Wilkinson, Blomfield Special School \(Secretary\)](#)

**Central:** [Daniel Price, Arahunga Special School, Whanganui](#)

[Diane Whyte, Fairhaven Special School \(Treasurer\)](#)

**Southern:** [Bernadette Mulcahy-Bouwman, Van Asch School, Christchurch](#)  
[Margaret Dodds, Waitaha Centre](#)

**NZEI REP:** [Barrie Wickens, Tauranga Special School](#)

**PRESIDENTS NEWSLETTER**

**22<sup>nd</sup>. August, 2018**

**Kia ora. Tēnā koutou katoa.**

**Dear Colleagues,**

The executive convened last week and we spent our usual very focussed day covering what we believe are important issues for our sector. Having members from all regions meet together results in the collation of a national perspective. Immediately following that meeting you received emails from the Exec. addressing current areas of concern and asking for your feedback.

**1: SEPANz Strategic Planning:**

The synopsis of this document was in the June Newsletter. the Executive revisited it and we are confident to take it to the MOOT in Wellington, set for the 23<sup>rd</sup> October. The essential elements are:

\*Our **Whakatauki** in Maori.

\***Vision:** ‘Personalized pathways for learners’,

\***Mission:** The statement taken directly from the SEPANZ Constitution.

\***Principles** The statements from 4.1 – 4.6 of the Constitution cover the principles.

\***Strategic foci:** **Principal Leadership, Collaboration and Connection, and Specialist Education Pedagogy.**

The Strategic plan is similar in format to that of the NZPF. Naturally it does not contain the fine detail that is found in our School Strategic planning. Organisational Strategic plans are designed to make a statement about our principles and be a FRAMEWORK from which Action planning can be developed.

**At the MOOT we are asking that you think of the broad principles upon which the SEPANZ Framework is constructed and then advise whether the draft SEPANZ Strategic document illustrates that vision.**

**We don't require "in-depth" details about what the organisation can set as Action plans – that would be a totally different conversation.**

**2: SEPAnz MOOT 23<sup>rd</sup> OCTOBER 2018 James Cook Hotel, Wellington:**

The day BEFORE the NZPF Conference!

**Please ensure that you are booked for this event!**

It will be followed by the NZPF Conference 24 -26 October, 2018.

We are hoping to invite and welcome, Bali Haige to speak with us about the vision and the work this far concerning "Tomorrow's Schools"

**3: SESTA:**

Daniel has represented SEPANZ members strongly during meetings. I, like others, have also had occasion to meet with Peter Grey and the staff from Wellington regarding some of the transport decisions made. I found that once all of the information regarding a Student's situation was clarified, either the transport was approved or at least everyone understood why it could not be approved. The other lesson has been knowing the importance of building an understanding relationship with our Learning Support Managers. A frank and open discussion with them prior to sending in what you consider a potential transport challenge, will achieve two things: firstly, the LS Manager can advise both the school and the SESTA people concerning the Child's needs. Secondly, the LS Manager can assist with problem solving. We are also aware that some of you have not received the support that you should – that is another concern.

Daniel's recent advice to all is sound. Please try and follow it in the hope that Transport applications for the 2019 start-up, will proceed more smoothly than this year. Please just ask if you would like some more information about how to complete the forms. Also work on that relationship with your LS Manager especially if you have some contentious applications!

**4: Curriculum Progress and Achievement Reference Group:**

SEPAnz is well represented on this group. Diane is an Advisory Group member and Bernie and Judith attend reference group meetings. The most recent series of meetings have resulted in some quite extensive planning. The intent makes sense and reference is made to individualised pathways and individual progress. 'Emerging Ideas' have been collated by the Advisory Group and sent distributed to the Reference Group. "Local design" is being supported for

Curriculum and Assessment development. An “Education Think Tank” is being recommended-to upskill schools about good practice. The MOE Curriculum Team has visited specialist schools and spoken at length with Teachers and Leaders at some of our schools which has been appreciated.

### **5: Outreach:**

Daniel distributed an email of a list of concerns to SEPANZ Members re the new Outreach Contract. Issues include: Outreach Teachers are not covered by Surplus staffing, Principal’s salaries do not include Outreach, Fixed term staff –Outreach staff do not qualify for laptops, Travel should be based on kilometres not a fixed amount. There is no relief teacher funding. Outreach Teachers are being asked to cover IWS – increasingly. The existing contract is a 3year term- we need an annual review of amounts payable. Due date of Outreach Contract – 20 August 2018.

Daniel has asked that each region fully discuss these anomalies and feedback to him. The feedback will contribute to a draft letter of complaint.

### **6: NELP (National Education Leaders & Principals)**

A meeting was convened with Iona Holsted, Secretary for Education, to ask for feedback regarding future planning for education. Iona shared the little information available – until the various reviews and working parties complete their work there is no real detail. We do know that the Ministry is looking ahead in three ways: the 2019 (immediate) planning, then planning for three years after that, and the huge 30 year plan.

Each of the various working groups fit into that schematic.

My discussions with Iona centred upon Hon Tracey Martin’s “SENCO” concept – as described in the June newsletter. Currently there is no planning for implementation. Initially a well-designed “series of pilots” would be set up should the concept proceed to the next step. As discussed with our West Auckland Colleagues, thoughts are that we will require an extensive professional development process to train these people, and that we don’t really need yet more “co-ordination/facilitation/bureaucracy” but rather, more people working directly with Children.

The success of the Outreach Service is due to the fact that knowledgeable Teachers spend the whole of the ORS time with the Student/class/teacher/support staff – whatever the classroom Teacher deems is needed to assist with the child. That is what our young people require– direct support.

Another aspect shared with Iona was the prevalency numbers. I have attached the document (below) that I sent to Iona following our meeting. Iona had attended a meeting decrying the fact that numbers of young people with ASD had increased – and the person had given a fairly common reasoning, which sounds highly credible and does not help our Young People one bit!

### **7: Professor Barry Carpenter:**

**Our Friend and Colleague, Prof. Barry has again generously included us in his Southern hemisphere lecture sojourn! Barry has offered to come to New Zealand prior to his Queensland event in June next year.**

Barry is looking forward to working with us all in June next year prior to his address to the ISEI conference (Early Intervention) 25-29 June 2019 in Sydney, followed by working with Queensland Specialist schools.

**Thank you sincerely to all of you who have immediately responded and indicated numbers of participants. Especially appreciate the South Island response – as it does mean flights and maybe accommodation in addition for you. We have kept the registration costs to an absolute minimum to make it doable for as many as possible. The Executive voted to use the Professional Development fund that was established following the CLICK wind-up, to pay for Barry’s fares and fee.**

## **Prof. Barry Carpenter: Saturday 22<sup>nd</sup> JUNE 2019:**

**NOT TO BE MISSED EVENT!**

**Specialist Educators Professional Development Opportunity with**

**Professor Barry Carpenter**

***Waipuna Hotel and Conference Centre, 58 Waipuna Road, Mt. Wellington, Auckland.***

Very best regards,

Judith

*Judith Nel,*

*SEPANZ President, Principal, Parkside School.*

### **For members of SEPANZ:**

#### **Information re: Autism Prevalence**

On April 26, 2018, the Centres for Disease Control and Prevention (CDC) released new data on the prevalence of autism in the United States. This surveillance study identified 1 in 59 children (1 in 37 boys and 1 in 151 girls) as having autism spectrum disorder (ASD).

**Description of System:** The Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence of autism spectrum disorder (ASD) among children aged 8 years whose parents or guardians reside the United States. ADDM surveillance is conducted in two phases. The first phase involves review and abstraction of comprehensive evaluations that were completed by professional service providers in the community. Staff completing record review and abstraction receive extensive training and supervision and are evaluated according to strict reliability standards to certify effective initial training, identify ongoing training needs, and ensure adherence to the

prescribed methodology. Record review and abstraction occurs in a variety of data sources ranging from general paediatric health clinics to specialized programs serving children with developmental disabilities. In addition, most of the ADDM sites also review records for children who have received special education services in public schools. In the second phase of the study, all abstracted information is reviewed systematically by experienced clinicians to determine ASD case status. A child is considered to meet the surveillance case definition for ASD if he or she displays behaviours, as described on one or more comprehensive evaluations completed by community-based professional providers, consistent with the Diagnostic and Statistical Manual of Mental Disorders, DSM-5 diagnostic criteria.

### **The limitations of indirect monitoring**

To estimate autism prevalence, the CDC uses a surveillance system called the Autism and Developmental Disabilities Monitoring (ADDM) Network. ADDM investigators estimate prevalence based on the educational and medical records of 8-year-olds at 11 sites across the country. The focus on 8-year-olds is based on the assumption that most cases of autism are diagnosed by that age.

A major limitation of the ADDM surveillance system is that it may miss children without records of an autism diagnosis or symptoms.

“There’s evidence to suggest that these numbers may still underestimate the true prevalence of autism in the United States,” says epidemiologist Michael Rosanoff, Autism Speaks director of public health research. “We need to understand why we may be missing autism cases in order to ensure that sufficient services are in place to support individuals across the autism spectrum and across the lifespan.”

### Data & Statistics

<https://www.cdc.gov/ncbddd/autism/data.html>

### **Prevalence**

- About 1 in 59 children has been identified with autism spectrum disorder (ASD) according to estimates from CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network. [[Read article](#)]
- ASD is reported to occur in all racial, ethnic, and socioeconomic groups. [[Read summary](#)] [[Read article](#)]
- ASD is about 4 times more common among boys than among girls. [[Read article](#)]
- Studies in Asia, Europe, and North America have identified individuals with ASD with an average prevalence of between 1% and 2%. [[Data table](#)]
- About 1 in 6 children in the United States had a developmental disability in 2006-2008, ranging from mild disabilities such as speech and language impairments to serious

developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism.

[\[Read summary\]](#)

### Identified Prevalence of Autism Spectrum Disorder

ADDM Network 2000-2014 Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)
2000	1992	6	6.7 (4.5-9.9)
2002	1994	14	6.6 (3.3-10.6)
2004	1996	8	8.0 (4.6-9.8)
2006	1998	11	9.0 (4.2-12.1)
2008	2000	14	11.3 (4.8-21.2)
2010	2002	11	14.7 (5.7-21.9)
2012	2004	11	14.6 (8.2-24.6)
2014	2006	11	16.8 (13.1-29.3)

[Learn more about prevalence of ASD »](#)

[Learn more about the ADDM Network »](#)

[Learn more about MADDSP »](#)

## Risk Factors and Characteristics

- Studies have shown that among identical twins, if one child has ASD, then the other will be affected about 36-95% of the time. In non-identical twins, if one child has ASD, then the other is affected about 0-31% of the time. [\[1-4\]](#)
- Parents who have a child with ASD have a 2%–18% chance of having a second child who is also affected. [\[5,6\]](#)
- ASD tends to occur more often in people who have certain genetic or chromosomal conditions. About 10% of children with autism are also identified as having [Down syndrome](#), [fragile X syndrome](#), [tuberous sclerosis](#), or other genetic and chromosomal disorders. [\[7-10\]](#)
- Almost half (44%) of children identified with ASD has average to above average intellectual ability. [\[Read article\]](#)
- Children born to older parents are at a higher risk for having ASD. [\[Read summary\]](#)
- A small percentage of children who are born prematurely or with low birth weight are at greater risk for having ASD. [\[Read summary\]](#)
- ASD commonly co-occurs with other developmental, psychiatric, neurologic, chromosomal, and genetic diagnoses. The co-occurrence of one or more non-ASD developmental diagnoses is 83%. The co-occurrence of one or more psychiatric diagnoses is 10%. [\[Read summary\]](#)

## Diagnosis

- Research has shown that a diagnosis of autism at age 2 can be reliable, valid, and stable. [\[Read summary\]](#) [\[Read summary\]](#)
- Even though ASD can be diagnosed as early as age 2 years, most children are not diagnosed with ASD until after age 4 years. The median age of first diagnosis by subtype is as follows. [\[Read article\]](#)
  - Autistic disorder: 3 years, 10 months
  - ASD/pervasive developmental disorder (PDD): 4 years, 8 months
  - Asperger disorder: 5 years, 7 months
- Studies have shown that parents of children with ASD notice a developmental problem before their child's first birthday. Concerns about vision and hearing were more often reported in the first year, and differences in social, communication, and fine motor skills were evident from 6 months of age. [\[Read summary\]](#) [\[Read summary\]](#)

## Economic Costs

- The total costs per year for children with ASD in the United States were estimated to be between \$11.5 billion – \$60.9 billion (2011 US dollars). This significant economic burden represents a variety of direct and in-direct costs, from medical care to special education to lost parental productivity. [\[Read article\]](#) [\[Read article\]](#)
- Children and adolescents with ASD had average medical expenditures that exceeded those without ASD by \$4,110–\$6,200 per year. On average, medical expenditures for children and adolescents with ASD were 4.1–6.2 times greater than for those without ASD. Differences in median expenditures ranged from \$2,240 to \$3,360 per year with median expenditures 8.4–9.5 times greater. [\[Read article\]](#)
- In 2005, the average annual medical costs for Medicaid-enrolled children with ASD were \$10,709 per child, which was about six times higher than costs for children without ASD (\$1,812). [\[Read summary\]](#)
- In addition to medical costs, intensive behavioral interventions for children with ASD cost \$40,000 to \$60,000 per child per year. [\[11\]](#)

## Highlighted Articles

- **[Key Findings](#)**

- [Feature Articles](#)

[Key Findings: Autism is Associated with Amount of Time Between Births](#)

A study from the Centers for Disease Control and Prevention (CDC) and research partners found that shorter and longer time periods between births are linked to having a child with autism spectrum disorder (ASD). The findings from this study can help healthcare providers convey information to their patients about the ideal timing between pregnancies. (Published: December 6, 2017)

[Key Findings: Prevalence of Self-injurious Behaviors Among Children with Autism Spectrum Disorder](#)

The Journal of Autism and Developmental Disorders has published a new study showing that nearly 28% of 8-year-old children with autism spectrum disorder (ASD) behave in ways that can lead to self-injury. (Published: October 21, 2016)

[Key Findings: Prevalence and Characteristics of Autism Spectrum Disorder Among 4-Year-Old Children](#)

Data from a CDC pilot project, published in the Journal of Developmental and Behavioral Pediatrics, suggest that progress has been made in identifying children with autism spectrum

disorder (ASD) at younger ages.  
(Published December 9, 2015)

[Key Findings: Autism symptoms among children enrolled in the Study to Explore Early Development](#)

A new analysis looking at autism spectrum disorder (ASD) symptoms among young children enrolled in CDC's Study to Explore Early Development (SEED).  
(Published June 6, 2015)

[Key Findings: The association between assisted reproductive technology and autism spectrum disorder](#)

New studies on the relationship between ART and autism.  
(Published March 20, 2015)

[ADDM Network update](#)

New CDC funding will expand knowledge about children with autism spectrum disorder.  
(Published January 2, 2015)

[Classifying autism in research studies](#)

Using standardized diagnostic instruments to classify children with autism to help find causes of the disorder.  
(Published October 27, 2014)

[Key Findings](#)

Unhealthy weight among adolescents with autism.  
(Published March 17, 2014)

[Risk Factors for Autism](#)

Read key findings from new CDC research.  
(Published: March 17, 2014)

[Key Findings](#)

Potential impact of DSM-5 criteria on autism spectrum disorder prevalence estimates.  
(Published: January 22, 2014)

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