



THE PERSONAL  
ADVOCACY  
**TRUST**  
INCORPORATED



February / Summer 2018

**What's On  
The  
Calendar?**

## March

### Quality of Service Survey

We would like to get the feedback of our members, their families and their staff, regarding the quality of our advocacy services. A survey will be distributed in late March 2018, in Easy-Read format to gather this information. Your participation would be greatly appreciated.

## April

### 11-12th April 2018

The Personal Advocacy Trust will be exhibiting at the New Zealand Disability Service Network Annual Conference.

## June

### 28 June 2018 - AGM

Following on from the success of our nationwide AGM last year, in June we will again be inviting all members, parents and families to join and participate in our AGM from around the country. You will be able to join either by attending a Regional Meeting of the AGM, or from any personal computer with an Internet connection. A full agenda and invitation will be distributed in May.

## The Trust Turns 50

On 4 December 2017 The Personal Advocacy Trust celebrated its 50th year of advocating for New Zealanders with Intellectual Disabilities. As with all good birthday celebrations there was some cake and bubbly, but there was also a moment taken to reflect on the work done by our predecessors to establish the Trust, the enormity of their task, and the survival, strength and fortitude of the Trust today as testament to the success of their efforts.

Though much of the membership from then has now passed, some of the Trusts current members have been enrolled for over 47 years, when their parents joined the Trust as far back as 1970.

Over the last 50 years we have learned many lessons along the way to help us improve and refine our advocacy services. Over the last 50 years we have ensured that our membership is heard. We have contributed to the successful resolution of legal and financially abusive situations, we have contributed to better healthcare and residential placement outcomes, and fuller community engagement and participation.

So at this momentous juncture in history The Personal Advocacy Trust would like to thank you for the support over the years, and thank you for your continued support to navigate the road ahead as the Trust readies itself for the next 50 years and beyond of advocacy support in New Zealand.



## New Trustees

At our 2017 AGM we bid farewell to Doug Langford who had volunteered his expertise as a Board Member and Trustee for The Personal Advocacy Trust for 14 years. At that time we also welcomed Catherine Cooke, a sibling to one of our members and who will fill the Trustee seat of Family/Contributor representative alongside the long standing Don Bagnall. Catherine was appointed following a nomination and election process involving all parents and contributors from around the country.

In November 2017 our eighth and final Board position was filled by John Stribrny, Chief Financial Officer of Te Roopu Taurima. John has been nominated by the New Zealand Disability Support Network to represent Residential Service Providers on the Board, as stipulated by our Trust Deed.

We are very fortunate to have such knowledgeable and skilled Trustees join us.

Our Trustees are:

Barney Cooper (Chair, Independent Seat), Don Bagnall (Family/Contributor Representative), Catherine Cooke (Family/Contributor Representative), Janine Stewart (IHC Representative), Gerard Letts (Law Society Representative), John Stribrny (Residential Service Provider Representative), Annette Brown (Independent Seat), Ross Steele (Independent Seat).

# System Transformation

Since 2008 various government agencies have been testing a number of approaches across New Zealand to provide disabled people with more choice and control over their disability support. These include the New Model, and two Enabling Good Lives demonstrations in Christchurch and Waikato. These have added layers to the existing disability support systems in these regions, and are steps toward a whole "system transformation". Representatives of disabled people, families, providers and government agencies have been working together to co-develop the design for the transformed system.

From 1 July 2018 the Ministry of Health will be leading a third demonstration of Enabling Good Lives in the Mid-Central Region (Palmerston North, Horowhenua, Manawatu, Otaki and Tararua Districts). This third demonstration will incorporate learnings about what has and has not worked well previously, along with including a social investment approach (investing money early where this will produce better life outcomes for people in the long term). Mid-Central will also be the area where the demonstration will first be rolled out as a whole of system change. Unlike in Christchurch and Waikato which only included small target groups in each area, any-one in the Mid-Central area who meets the Ministry of Health's Disability Support Services eligibility criteria – which includes all of our membership – may be eligible to access support under the transformed model. Close monitoring and evaluation in mid-Central will help ensure there is on-going refinement in mid-Central, and to inform the eventual replacement of the nationwide system.

The transformed system will be based on the vision and principles of Enabling Good Lives, to provide disabled people with more choice and control over their lives and the support they receive. The transformation will build on existing capability, capacity and expertise, but the supports available and way families approach these supports may look very different in the future. Funding from the Ministries of Health, Social Development and Education will be pooled for allocation to those who are eligible. Disabled people then can gain access to flexible funding to be used for a variety of things including but not limited to community activities, supports, or employing people. Disabled people will be supported to make more use of natural and universally available supports to access "everyday life in everyday places," rather than focusing on 'special' places or activities for disabled people. The Ministry will also be investing in new functions, such as independent facilitation, whilst also changing some existing functions, such as assessment and allocation processes through NASC.

At this stage in the system development process, it is unclear how things will change for those of our membership who may not be able to self realise or exercise more choice and control over their lives, due to their significant or complex disabilities. The Personal Advocacy Trust is committed to engaging with the process to try to ensure this group's voice is represented and their needs can be catered for in this system transformation.

The information for this article was gathered from the website of the Office of Disability Issues, [www.odi.govt.nz](http://www.odi.govt.nz). More information can also be found at [www.enablinggoodlives.co.nz](http://www.enablinggoodlives.co.nz), or by contacting your Regional Advocate.

## Did you know...

...The Personal Advocacy Trust can administer Discretionary Trusts for its membership? Many parents wonder how they will be able to provide for and protect the financial security for their son or daughter with an Intellectual Disability after they have died.

Discretionary Trusts allow for funds to be held and used exclusively for the benefit, support and wellbeing of the named beneficiary. Safeguards and disbursement approval processes ensure funds are not prematurely depleted or abused. Discretionary Trust funds administered by The Personal Advocacy Trust are securely invested, accounted and reported on, and are easily accessible to the beneficiary - the member, by application to the Board. The Personal Advocacy Trust charges a nominal 1% annually for this service, with nil application, disbursement or administrative fees.

Discretionary Trusts may be established for members at the time of enrolment or anytime thereafter, including through Testamentary will. It is advisable that a Letter of Wishes be supplied as an important document with your instructions as to how you would like your Trust to be administered or distributed after your death. Discretionary Trusts may have their own Trust Deed drafted, or alternatively can operate under the mandate and protocol of The Personal Advocacy Trust Deed.

For further advice on how to establish a Discretionary Trust for your son or daughter, or on how to leave a bequest to The Personal Advocacy Trust in your Will, please get in contact with the National Director on 0800 728 7878.



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Do we have the right contact information for you? To update your or your family members details please get in touch:

[www.PAT.org.nz](http://www.PAT.org.nz)

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