

# Families for Change

Promoting and defending  
the rights and interests  
of people with  
developmental disability.

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family

A D V O C A C Y

## Systems Advocacy – Changing the System

This edition of *Families for Change* focuses on systems advocacy - advocacy aimed at the 'systems' that impact on the lives of people with disability. Systems advocacy attempts to influence policy and legislation at the government and bureaucratic levels, as well as at the service delivery level.

The systems that frame the lives of people with disability today were introduced by politicians and bureaucrats with the best intentions. But often the people who write policies and create budgets know very little about the day to day life of a person with disability. Historically, people in authority have failed to understand the subtleties of what having a good life for a person with disability involves, and have focused on the concepts of shelter, education and employment in only a very basic and superficial way, creating the facade of a good life but with very little substance behind the veneer.

Over time, the wider community has accepted government policy as the benchmark for what is right and acceptable for people with disability. Most people don't question the underlying assumptions that form the basis of the rationale behind group homes, sheltered workshops or special schools. But these services are based on the congregation and segregation of people with disability, practices that have been shown to do harm to already vulnerable people. In turn, when families and the wider community do witness the damage that these practices can cause, they feel powerless to challenge 'the system' because it is so immense and faceless.

Systems advocacy embraces the idea that the 'rules' that govern the way people with disability live are not 'a given' and can be challenged.

In general, human beings are resistant to change. Especially when the change is counter to everything we were brought up to believe (she won't cope in a regular class, he should be with his own kind...).

So changing the 'rules' is a very difficult and slow process, because we are not only changing systems but also perceptions.

***Systems advocacy embraces the idea that the 'rules' that govern the way people with disability live are not 'a given' and can be challenged.***

It is important to challenge out of date ideas because not only do they influence government policy, they also encourage a certain mindset: the deficit model way of thinking, where people are considered in terms of what they can't do instead of what they can achieve. In this model, people with disability rarely have the opportunity to choose where and with whom they live, pursue interests, find meaningful work or develop friendships with people in the wider community.

Working on a large scale is as difficult as it is important. It takes many meetings with senior bureaucrats, deputations to see a Minister; written submissions to Inquiries; memberships of Committees; campaigns, and many, many letters. Sometimes the focus is as much about not going backwards as it is about moving forward. Recent moves to redevelop large institutions illustrate how easy it is for people in authority to return to dated practices in relation to how people with disability should live.

The contributors to this edition of *Families for Change* give an overview of some of the systemic advocacy currently taking place. In her article, *Working towards meaningful change*, Belinda Epstein-Frisch describes the systems advocacy work undertaken by Family Advocacy. People with Disability (PWD) have been involved with the development of the United Nations Convention on the Rights of Persons with Disability and in the article *Using Human Rights*

*Framework for Systemic Advocacy*, Sonia Price-Kelly discusses how the Convention can be put to work. Victoria is moving ahead on many disability issues and David Craig, Executive Officer for Action for Community Living, provides a Victorian viewpoint in his article *Action for Community Living: A Victorian agency's perspective*. Finally, in the article entitled *Advocacy through research and development*, Mark Pattison from the National Council on Intellectual Disability discusses the focus of his agency's systemic work.

In the course of Family Advocacy's systems advocacy, we invite families to participate in inquiries and meetings, and step from the private into the public domain. We acknowledge it is often difficult to speak out and wish to thank the families and allies who participate, and in doing so, give life to the quote from American anthropologist, Margaret Mead:

*Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.*

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# National Council on Intellectual Disability Systemic Advocacy Through Research and Policy Development

Mark Pattison

*Mark Pattison has been the Executive Director of National Council on Intellectual Disability (NCID) for 14 years. Before joining NCID, Mark managed support services in South London for five years, providing residential, employment and integrated health services to people with disability leaving institutions to go into community life. Mark pioneered the creation of non-profit community purchasing agencies and the creation of community support agencies. Before moving to the United Kingdom, Mark managed residential services in Australia including the development of community services for people leaving institutions.*

The National Council on Intellectual Disability (NCID) was established over 30 years ago by parents and friends to improve the quality of life of people with intellectual disability by providing national unity and information. Its mission is:

*to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.*

NCID has two guiding principles:

1. All people are valued members of the Australian Community.
2. People with intellectual disability as equal participating members of the Australian Community have the same rights:
  - to participate in decisions which affect their lives;
  - to pursue any grievance which affects their lives;
  - to diversity of choice for housing, education, work, recreation and leisure;
  - to equity and justice;
  - to be empowered to take their full place in the Australian Community;
  - to dignity and privacy in all aspects of their lives.

In practice, this means that NCID focuses on 3 essential elements.

1. To represent to the Australian Government and the Australian community the many views of people with intellectual disability and their families. NCID's role is

not to support or advocate for a particular point of view; though NCID does have a responsibility to promote the active participation of people with intellectual disability in the community and their rights and responsibilities as citizens.

## ***One of the current debates is whether governments should fund outcomes that do not meet international and national best practice outcomes?***

2. To have a major role in promoting good practice based on positive outcomes for people with intellectual disability
3. To have a major role in publishing research and promoting policy and funding decisions based on evidence of positive outcomes for people with intellectual disability.

How does NCID achieve the above?

NCID continually consults with our members both formally and informally. NCID has over 5,000 members representing all States and Territories. In addition, NCID receives advice from 'Our Voice', a committee which comprises only people with an intellectual disability.

NCID has an active network of members, friends and supporters who respond to our submissions and reports and commit to ongoing discussions that enable us to 'tease out' all the issues. An example of

this kind of consultation would be the recent work on Special Disability Trusts. The submission was the work of a group of people with specialist knowledge and experience, who guided NCID through the complex issues and proposed constructive solutions.

When a major issue arises, or resurfaces, NCID undertakes or coordinates research on the issue and then produces a policy paper. Last year NCID investigated issues associated with education and quality assurance with reference to employment.

As NCID receives a portion of income from the Australian Government, it has a responsibility to prepare reports and submissions to parliamentary inquiries and Australian Government initiatives. For example, NCID recently made submissions to the Supported Employment Review, Senate Inquiry into the Special Disability Trusts and the House of Representative Inquiry into Support For (Carers) Families.

Major work for NCID in 2008 and 2009 will include research on the transition from school to employment, policy development on an entitlement to employment support, implementation of self directed support and translating the recently ratified UN Convention on the Rights of People with Disability into an action document so that people with intellectual disability are fully represented in the Australian Government's proposed National Disability Strategy.

As a peak body, NCID is able to support advocacy (at both individual and systemic levels) by representing the range of views and placing these views

within the context of both national and international 'best practice'. This means that NCID is able to discuss with all the interested parties the best outcomes for people with intellectual disability and how to achieve them.

One of the current debates is whether governments should fund outcomes that do not meet international and national best practice outcomes. In considering

this, NCID has asked its members about the current practice in other community services, such as health, education and defence. If government treasuries approached disability support in the same manner that they approached other areas of expenditure – with effectiveness and efficiency as their guiding principles - what disability support models would they fund?

NCID's actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. It is not the Council's role to tell people how they should be supported. Our role is to verify which practices will achieve the best outcomes for people with intellectual disability.

# Working Towards Meaningful Change

**Belinda Epstein-Frisch**

*Belinda Epstein-Frisch has worked as a systems advocate for Family Advocacy for the past 14 years, negotiating with government on the rights and interests of people with disability, particularly on the issues of children and young people, supported living and devolution. Belinda holds a Masters degree in Social Work and has 30 years experience in community development, social policy and administration in human services.*

Family Advocacy has a vision that families can create positive social change, so that people with disability can have a good life and experience the same opportunities that other Australians enjoy. All of Family Advocacy's activities are targeted toward this goal.

'Unpacking' our vision exposes the plethora of work that is necessary. How do we help families to have a positive vision? How do we foster meaningful change in our society? How do we change the systems and institutions that have developed around people with disability, albeit with good intent, but which are impersonal, restricting and outdated?

Working towards meaningful change requires that we understand and address the systems that operate around people, hence the term 'systems advocacy'. How do systems thwart the vision of families? What do we really want the systems to do? How do we really want to be supported?

The answers to these questions, based on our knowledge of the lived experience of people with disability, underpin our systems advocacy work. It is formulated around these priorities:

- children being welcomed and educated in the regular class at their local school and embedded in the life of that neighbourhood and wider community;
- people participating in *meaningful* work and leisure;
- people living in the home of *their* choice, with people that they choose and with security of tenure;

- people having meaningful relationships with people who care about them through school, work and community;
- families feeling supported with all family members getting what they need;

***Working towards meaningful change requires that we understand and address the systems that operate around people, hence the term 'systems advocacy'.***

- safeguards in place to protect people with disability from harm.

Our newest priority, building relationships for people with disability and their families, was developed through an understanding of the importance of relationships. Relationships keep people safe and lead to the creation of a rich and meaningful life. They are also at the core of quality supports. So, how do we foster meaningful change in the social service system in order to move towards this goal?

If success is described as the social service system being grounded in processes and practices that enable people with disability and their families to be enriched by relationships with people who care about them, then Family Advocacy must advocate to:

- assist families to recognise the value of relationships and to support them with strategies to foster relationships for and with their family member with disability;
- help services and government recognise that the service system, as currently constituted, is an impediment to this success and hence recognise the need for change;
- change the culture, policy and practice of service providers to value relationships and provide staff with the knowledge and skills to foster relationships;
- change the policy and practices of government to facilitate a service system that values relationships.

Family Advocacy has undertaken many strategies to change 'the system' so that the lives of people with disability and their families can be enriched and safeguarded by relationships. International human services consultant, Michael Kendrick identifies four key ingredients of systems change. These include:

- leadership at all levels;
- inclusion of stakeholders;
- the equalization of knowledge;
- sustainability.

These ingredients are interdependent and effort must be long term to ensure sustainable change to the attitudes and values, policies and practices of systems.

Family Advocacy actively develops and supports leaders from many walks of life. Our leadership development program focuses on providing opportunities and support for parents and other family members to assume leadership roles within the organisation and in moving from the private to the public domain in speaking out on systemic issues.

In our systems advocacy work, we meet with bureaucrats, politicians and senior people in the service system to nurture their leadership around an alternate vision. We recognise that readiness for change, both in the cultural and political sense, does not occur until enough people in enough constituencies create a mandate for action. So a key strategy is to help people acquire the knowledge that something different is desirable and possible.

One way of doing this is by running workshops for families that showcase

people with disability leading valued lives in which paid support is used to complement rather than drive out informal support built on relationships. Other strategies have included the development of websites, the circulation of print and visual media and the presentation of papers at conferences.

Simultaneously, we expose bureaucrats, politicians and service providers to vision building opportunities. We showcase stories and systems from other parts of Australia and overseas which foster the development of relationships as a key part of delivering quality supports. We have held three Roundtables for Ministers, their staff and senior bureaucrats which brought together Australian services that have broken new ground in giving support to people with disability. We have facilitated opportunities in which families have shared their vision and

discussed the implications for the service system with key Ministers and bureaucratic decision makers.

Family Advocacy has outlined strategies for small scale trial projects and for large scale systems transformation. We are working energetically and small projects have begun to take up the challenge of the change that is required. As yet there are not enough people in enough constituencies to create a mandate for systemic change and so the question of sustainability is one for the future.

Family Advocacy's actions and the examples we showcase consistently demonstrate, however, that having families and advocates working together with systemic players is critical to delivering change that actually benefits people with disability and their families.

# Using a Human Rights Framework for Systemic Advocacy

Sonya Price-Kelly

*Sonya Price-Kelly is the Senior Advocate – Systemic Advocacy at People with Disability (PWD). She has worked in the disability sector since 1991, as a direct support worker in day program services and as Information and Community Liaison Officer at the New South Wales (NSW) Council for Intellectual Disability. She was employed in Licensing and Policy related roles in relation to boarding houses within the Department of Ageing, Disability and Home Care, and has worked in the Disability Reviewable Death Team and as a Community Visitor Liaison Officer at the NSW Ombudsman.*

People with Disability Australia Incorporated (PWD) is a national peak disability rights and advocacy organisation based in Redfern, Sydney. PWD's vision is that of a socially just, accessible and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are respected and celebrated. Our purpose is to be a leading disability rights, advocacy and representative organisation of and for all people with disability. PWD strives for the realisation of its vision through a range of activities including:

- information services;
- consumer protection;
- education and training;
- individual and group advocacy;
- systemic advocacy.

This article will highlight PWD's role in systemic advocacy, providing a few key examples of how it uses this particular mechanism to further its fundamental role in responding to the vulnerability and disadvantage often experienced by people with disability.

## Key Frameworks

Systemic advocacy is often defined as action taken to break down a barrier that is preventing a group of people from having their needs addressed. Given that systemic advocacy aims to achieve both universal and fundamental positive change in a society and its structures, it is essential that it has a strong foundation.

PWD's foundations for its systemic advocacy lie within two key frameworks – the 'social model of disability' and

human rights. The 'social model of disability' is an approach that locates the problem or issue of concern within the environment or society as opposed to the perceived ability or disability of the individual person. This approach is used to describe the physical, cultural and attitudinal barriers which limit the opportunity and participation of people with disability.

The value of this approach, coupled with a human rights perspective, lies in its recognition of people with disability's potential and diversity, and that every person has inherent dignity and value.

This position of principle underpins PWD's use of human rights conventions and treaties as tools for addressing the day to day discrimination, marginalisation and abuses that confront

people with disability. It is reflected in the broad range of systemic advocacy it undertakes at international, national, state and local levels.

**Systemic advocacy on a large scale**

An example of how systemic advocacy works on both an international and national scale has been PWD’s involvement in the development of the United Nations Convention of the Rights of Persons with Disabilities (UN CRPD). PWD was involved in the process of developing the Convention at the UN in New York over a number of years. Over the past year and a half, often in collaboration with other disability organisations, PWD has strongly advocated for the ratification of this Convention by the Australian Government. It is, therefore, immensely encouraging that Australia has ratified the UN CRPD, which in turn will impact on how laws, regulations and policies will relate to people with disability in our country.

Strong advocacy has also been made around the use of the UN CRPD by the Australian Government as a key framework for new initiatives such as the Rudd Government’s National Disability Strategy, the National Mental Health and Disability Employment Strategy, the Homelessness Agenda and the Social Inclusion Agenda to name but a few.

PWD also aims to participate in the non-government reporting process to the UN, a process known as ‘shadow reporting’. This process allows the non government organisation sector to comment on how well it considers Australia to be upholding the rights of its citizens against each of the Conventions or treaties it has signed.

**Building the capacity of Regional Partners**

Through its capacity building role, PWD has also assisted to broaden the knowledge and understanding of Human Rights frameworks to people with disability in Pacific Nations. Earlier this year, in partnership with the Pacific Disability Forum, PWD secured funding from the Asia Pacific Forum of Human Rights Institutions (APF) for a Rights and Capacity Building forum for women with disability. This forum, held in Samoa in April this year, was attended by approximately 44 women from Pacific Island countries.

The women not only gained an individualised perspective of their rights, but also a better understanding of how these individual rights fed into the development of local charters, National Constitutions, and in time matured into international declarations of human rights. Importantly they also gained an understanding of how these mechanisms can be used to reinforce the rights of people with disability and create change.

**Taking a local focus**

It is not just at an international and regional level, however, that these human rights frameworks can be used to safeguard the human rights of people with disability. PWD also uses the CRPD in a number of ways to frame its work at a more local level. For example, as a key advocacy tool PWD progressively develops its own policy positions on the key rights contained in the Convention and uses these to influence the NSW Government’s understanding of these rights and how they may be implemented.

PWD also regularly makes submissions to both Federal and State Parliamentary inquiries and reviews and participates in committees, roundtables and other forums. Through these processes it

commonly makes reference to the CRPD and other conventions as a way to promote and strengthen the rights of people with disability.

One final example of how PWD references and reflects on human rights frameworks with a social model approach is through its systemic advocacy project work. Illustrative of this is a project currently being undertaken in partnership with the Disability Studies and Research Centre which focuses on barriers to the realisation of human rights of freedom from abuse, neglect and exploitation for people with a cognitive impairment.

**Achieving equity and equality**

Systemic advocacy by its very nature is something that takes both time and persistence. With this in mind, systemic advocacy approaches benefit from having strong foundations. PWD believes that a human rights approach provides these foundations as well as being a powerful tool to achieve its aim of equity and equality of people with disability.

For more information on PWD and its activities please refer to our website [www.pwd.org.au](http://www.pwd.org.au) or contact our office on (02) 9370 3100.

**Email communication**

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# Action for Community Living: A Victorian Agency's Perspective on Current Issues

David Craig

*David Craig commenced work in the disability advocacy sector with an Action for Community Living (ACL) program called the Victorian Network on Recreation and Disability (VICNORD). After a brief time, he became the Executive Officer for ACL, a position he has held for the past eight years. Prior to ACL, he worked for 18 years with the Spastic Society of Victoria (now Scope Victoria) in the development of community based recreation and leisure opportunities for people with disability.*

Action for Community Living (ACL) is an organisation of people with disability that is funded to undertake systemic advocacy around the promotion and protection of the human rights and well being of people with disability in Victoria. ACL began as a campaign for the establishment of attendant care support services to enable people with disability to live their lives in the community and to experience the freedoms, rights and opportunities afforded other citizens. With the establishment of funded attendant care programs across federal, state and local government in the late 1980s to early 1990s, ACL's attention was broadened to address a wider range of issues that needed systemic advocacy.

The key focus of this early work included the push for inclusive education, the extension of attendant support services and provision of individualised funding, campaigns for the closure of institutions and lobbying for open employment opportunities.

Initially ACL's systemic advocacy work was led by paid advocates employed by the Committee of Management. Around 2000, the Committee became concerned about the limitations of the 'professional model of advocacy' and decided to shift to a more participative model incorporating community development principles. ACL sought to link systemic issues with the direct experience of individuals who were facing disadvantage, risk or discrimination. Action Groups were formed in the context of tackling a specific issue and individuals were supported to develop advocacy skills and knowledge with the help of systemic advocates.

Our current systemic advocacy priorities have been largely built around:

- ongoing challenges of quality of attendant support services and other disability support programs;

***As the Rudd Government opens up the social policy agenda, with a focus on Social Inclusion, there is also a need to for us to identify disability issues within the broader social context of poverty, housing and employment.***

- countering the negative impacts of occupational health and safety management frameworks applied by support agencies in this sector;
- the introduction of individualised funding packages with increased choice and control for service users;
- disability services legislation reform in Victoria;
- closure of Kew Cottages institution;
- the Younger People in Nursing Homes campaign;
- improving access to the built environment promoting universal design principals;
- the Unmet Needs campaign for more disability support funding;
- promoting the national development of the Companion Card Scheme;

- promoting access to open employment in public and community sector agencies for people with disabilities currently finding access to a job impossible;
- increasing access to leisure and aquatic facilities and programs.

As we prepare for a strategic planning phase, some of the considerations for how we might strengthen our systemic work include:

- make a greater impact with our systemic advocacy;
- find a good balance between proactive systemic change and reactive work that is both responsive and of a monitoring nature;
- endeavour to better understand the political, social, economic and cultural context in which we work and how we can better adapt our strategies to match this analysis. This includes developing new skills in the use of new forms of media;
- strengthen the evidence for our arguments for policy changes through improved research and social policy work;
- better target our limited resources to improve the quality of both our process and our effectiveness;
- support sector development and better collaboration across the nation with other systemic advocacy groups, both within the disability sector and across the community sector.

The emergence of the universal disability insurance issue on the Prime Minister's 2020 agenda suggests that some of the

key matters we have been advocating for might come together around self determination, individualised funding and an entitlement to disability support. While the objective is an ambitious one, the timing seems to be right for a challenge to:

- the current complexity and waste in funding administration;
- large waiting lists for basic disability support;

- restrictions around where you can live or move based on which level of government provides the funding.

As the Rudd Government opens up the social policy agenda, with a focus on Social Inclusion, there is also a need to for us to identify disability issues within the broader social context of poverty, housing and employment. ACL will endeavour to raise disability issues within the integrated social

policy agenda, rather than supporting the marginalisation of these issues by accepting their placement on a separate disability agenda.

We particularly look forward to the establishment of Disability Advocacy Network Australia and the promise of collaboration, development and strengthening of our collective advocacy effort for people with disability and their families.

## A Life of Achievement

*National Disability Award winner, musician, artist and mountain climber, Joel Satherley, lost his battle with cancer and passed away at his home in Lismore on June 25, 2008 surrounded by those who loved him. Joel was 24.*

Joel will be remembered for his courageous spirit, persistence, unfailing good humour and joy for life. Joel's glass was always half full and never half empty.

His life was one of achievement against the odds. As a young boy, Joel was refused admission into the regular class of his local school, because of his disability. After countless phone calls to schools throughout New South Wales (NSW), he was accepted by Nimbin High School and never looked back. Rather than being wounded by the experience of exclusion, Joel and his family were able to turn the situation around, and made a short film called *Joel's Story*. It demonstrated the positive effect that mainstream education had for Joel and his acceptance into school and his broader community. *Joel's Story* has been seen by hundreds of families and continues to inspire and encourage parents of children with disability.

Joel loved music and played keyboards. He loved to busk in Lismore's city centre and had a regular radio slot on NIMFM. He also recorded a disk of his own musical improvisations which has sold successfully. As a TAFE student, Joel performed in plays and did stand up comedy at the local comedy club. His affinity with the arts also included painting and he had exhibited in local art galleries and was preparing for a solo exhibition.

As a presenter at Family Advocacy's conference *The Odyssey... a journey of enrichment*

*and possibility*, in October 2007, Joel told his story of climbing the sacred mountain Wollumbin (Mt Warning) in Northern NSW. Joel described the gruelling 10 hour hike, and how with the help of 35 volunteers, he was able to achieve his goal, which many thought was impossible. He encouraged families to re-think the conventional ideas around recreation for people with disability and to build a vision of what could be more fulfilling, challenging and fun.

In December 2007, Joel was presented with a National Disability Award for Personal Achievement, acknowledging his accomplishments and the contribution that he made to his community.



Joel at radio station NIMFM

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## Family

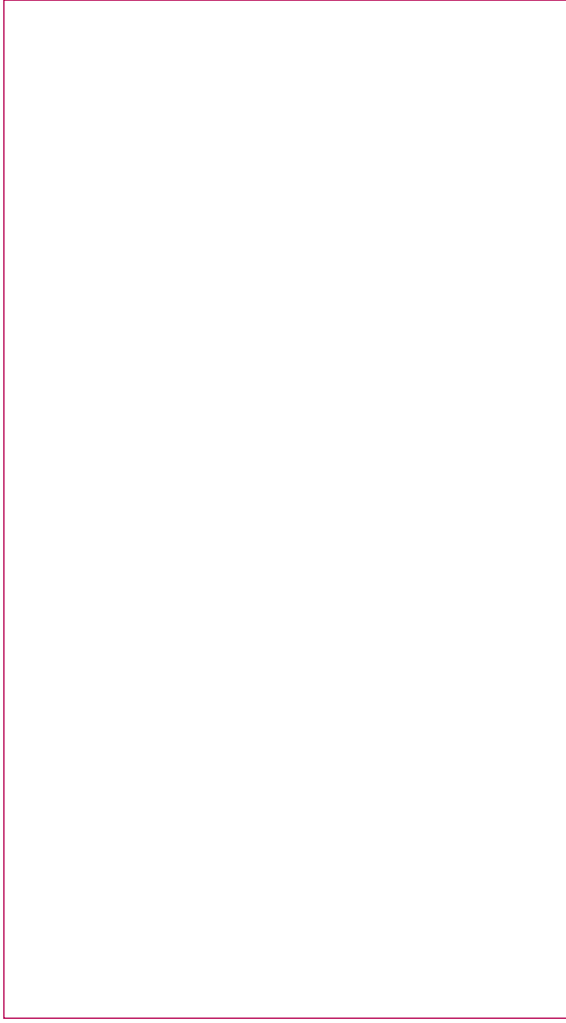
Groups which actively and powerfully shape society and within which there are unique individuals who share challenges, changes, struggles, failures, and successes... and sometimes dreams.

## Advocacy

Standing alongside an individual who is disadvantaged - and speaking out on their behalf in a way that represents the best interests of that person.

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