

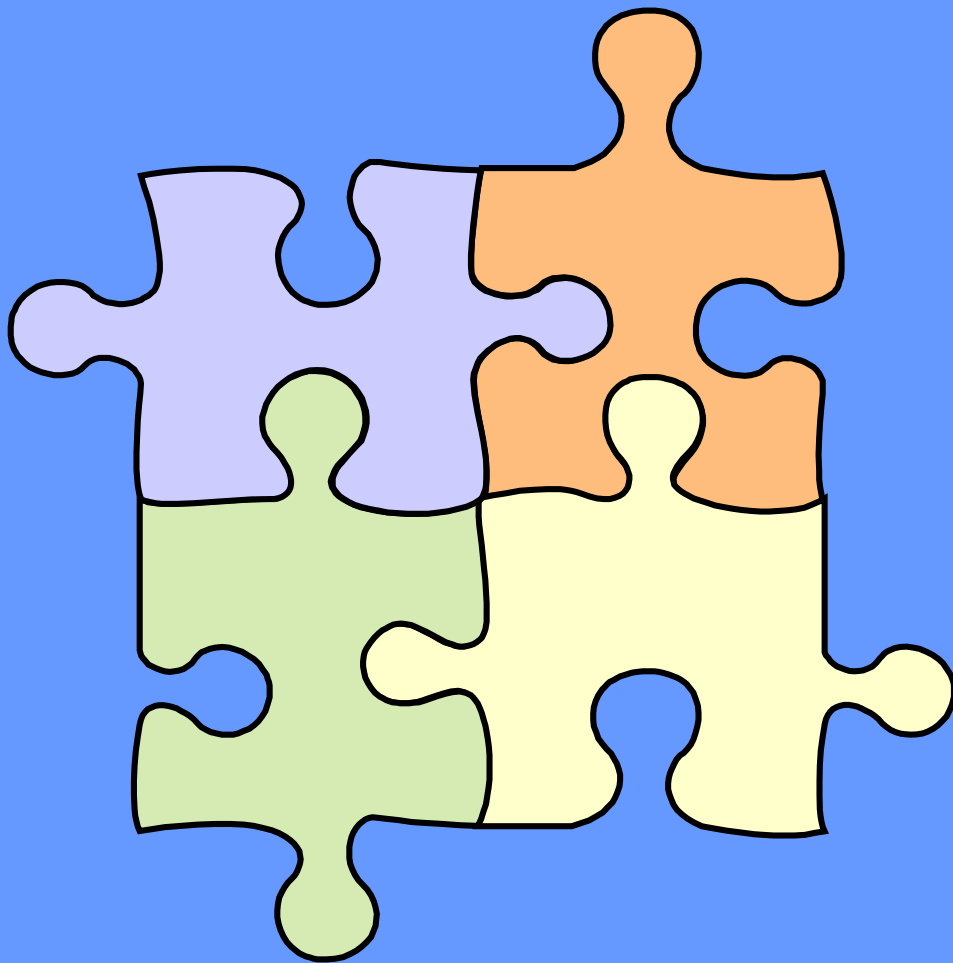
NPSA

National Parents
& Siblings Alliance



Campaigning for the Rights of People with Intellectual Disability and Autism...

Background & Strategic Plan 2009 - 2012



The NPSA

The *National Parents and Siblings Alliance* ('The NPSA') was founded in 1998 out of recognition that there was a need for a unifying voice for the parents and siblings of the 25,000 people with an intellectual disability and autism living in Ireland. A national advocacy organisation the NPSA works in co-operation with other disability organisations throughout the country.

Since its establishment the NPSA has been at the forefront of the campaign for the right to equal opportunities for people with an intellectual disability and autism. From the outset it sought to establish a consensus for a charter of rights for people with disability based on the essential elements felt necessary to reflect its vision for people with intellectual disabilities and autism. Essentially the 'Charter' constitutes the main purpose of the NPSA.

The NPSA is a non-profit organisation wholly dependant on the voluntary support of its members, indirect State funding (National Lottery Fund) and corporate and individual donors.

Our Vision

The vision of the NPSA is to secure a good quality life for people with intellectual disability and/or autism. That is, a place of their own or a secure living space in a caring environment, financial security, choice and the opportunity to make a meaningful contribution to Irish Society. We visualise a future, based on the NPSA 'Charter of Rights', where our sons', daughters' or siblings' wishes and choices are respected and that they can live a life that is safe and secure and free from abuse, exploitation, isolation and loneliness.

Our Mission

The mission of the NPSA is to be an independent national organisation and achieve its vision through informing, supporting and advocating for and on behalf of the person with intellectual disability and/or autism and their families.

What We Have Done to Date

After our foundation the NPSA quickly established itself as a driving force for change. Operating with limited resources we built a formidable track record of achievement. Our strategy was to campaign and advocate in a highly visible and vigorous style with a focussed critique of Government policy and service delivery practices.

In 1999 we ran the “One Penny More” campaign. This successful campaign aimed at convincing the public and the Government that a 0.1% increase in tax would eliminate waiting lists for disability services. It succeeded in persuading the Government to initiate the “Cowan Plan” which went some distance towards resolving the worst waiting list problems at the time.

2001 saw two major tasks for the NPSA. We prepared our own disability legislation called The Disability Commissioner Bill 2001. This was debated in the Dail but was defeated by the Government because they were about to publish “superior” legislation. The “superior” legislation, the Disability Bill 2001, was seen by the disability community as being anti-disability and, following a strong campaign by the NPSA and others, it was withdrawn in February 2002.

From 2002 we have been involved in presenting the views of our member groups during the period that the Disability Bill and the Education for Persons with Special Educational Needs Bill were being prepared and were progressing through the Dáil. Both Bills were subsequently enacted and while representing a welcome momentum toward achieving equal access to basic rights for people with intellectual disabilities and autism they remain fundamentally flawed and consequently have not had a material impact. We have vigorously represented the strong reservations of the disability community about both pieces of legislation and continue to do so.

From the outset we have acted as advocates for people in their struggle for basic services for their children and family members. Even the strongest of our members can get worn down by the endless fight for services and the worry it brings. This is an ongoing and essential element of our activities.

We have and continue to be an influential force on many national committees concerned with disability. They include The Disability Legislation Consultation Group, The NDA National Standards for Disability Services Committee and the Department of Health and Children National Monitoring Committee on Spending in the Areas of Intellectual Disability and Autism.

A core objective of the NPSA is to educate and transform societal attitudes towards people with intellectual disabilities and autism. 2007 saw the publication of the findings of the first ever commissioned research on best practice in respite provision in Ireland, the production and distribution of educational DVDs on understanding ADHD and Aspergers Syndrome. In 2008 we hosted the first ever comprehensive conference on individualised funding as an alternative model for state services.

NPSA Charter of Rights

People with intellectual disabilities and/or autism have:

1. a right to live and be recognised as independent people with the freedom to enjoy, in a caring and loving environment, their civil, economic and social rights in equity with all other people, regardless of age, gender or disability;
2. a right to resources and support [from the State] appropriate to the needs of the individual and in this context:
 - 2.1. a right to a detailed assessment of their needs and to comprehensive, individualised (self directed where appropriate) medical, social and living support;
 - 2.2. a right to an appropriate education geared to their potential and abilities;
 - 2.3. a right to training and/or further education;
 - 2.4. a right to rewarding and satisfying employment where appropriate;
3. a right to be free from discrimination and from economic, sexual, or other forms of exploitation;
4. a right to cast their vote or have their vote cast by their legal guardian or carer.

People with intellectual disabilities and/or autism, their parents, guardians and siblings have:

5. a right to participation and consultation in the formulation and implementation of all policies which affect their lives;
6. a right to select and determine, in consultation with service providers and professionals, in a timely and planned manner, the support services and infrastructures they require;
7. a right to participation in the governance and direction of all service organisations charged with the provision of support services, including all statutory agencies.

The parents, guardians and siblings of people with intellectual disabilities and/or autism have:

8. a right to information and consultation about the needs of their family member, irrespective of age and, where appropriate, to be heard and their wishes acted upon;
9. a right to counselling, support and respite care when needed;
10. a right to respect, recognition and compensation for the roles they play.

NATIONAL PARENTS & SIBLINGS ALLIANCE

STRATEGIC PLAN 2009 - 2012

1. AGENTS OF CHANGE

Perhaps the key reason d'etre of the NPSA is to act as agents of change. This activity stream is central to our mission and characterised by critical analysis of the disability environment in Ireland in particular the National Disability Strategy (NDS) and interventions in the national discourse on policy development.

Inputs	Activities/Strategic Objectives	Medium Term Outcomes
1 (a) Critically monitor the roll-out of the NDS		
<ul style="list-style-type: none"> ● We are parents/ family of people with disabilities and/or autism. 	<ul style="list-style-type: none"> ● Maintain a database on the rollout/implementation of the NDS 	<ul style="list-style-type: none"> ● Establish a system of monitoring/taping into available information sources such as: Government websites, other associated websites, HSE websites, consultative committees and our own membership.
<ul style="list-style-type: none"> ● We have an established net-work of members across the State. 	<ul style="list-style-type: none"> ● Actively participate in national/regional monitoring committees as appropriate. 	<ul style="list-style-type: none"> ● Have representatives sitting on all major national and regional monitoring committees.
<ul style="list-style-type: none"> ● We have strong links with the major disability representative organisations in the State. 	<ul style="list-style-type: none"> ● Produce an annual report on the NDS 	<ul style="list-style-type: none"> ● First annual report December 2009.
<ul style="list-style-type: none"> ● We have access to the major service providers for people with intellectual disability and/or autism (service providers). 	<ul style="list-style-type: none"> ● Maintain/develop contacts with people at ground level as a two way process of information flow/dissemination. 	<ul style="list-style-type: none"> ● Establish a consultative meeting series at local/ground level.

Inputs	Activities/Strategic Objectives	Medium Term Outcomes
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1 (b) Critically examine funding and structures for service support

<ul style="list-style-type: none"> ● We have access to the major disability research centres in Irish Universities. 	<ul style="list-style-type: none"> ● Monitor national and international trends and initiatives. 	<ul style="list-style-type: none"> ● Have established a process of regular consultation/communication and interaction with research centres, service providers, government bodies and other disability organisations.
<ul style="list-style-type: none"> ● We have links with the major disability representative organisations in the State. 	<ul style="list-style-type: none"> ● Promote understanding of alternative structures/benefits/drawbacks. 	<ul style="list-style-type: none"> ● Host a major conference on alternative funding models.
<ul style="list-style-type: none"> ● We have access to the major service providers. 	<ul style="list-style-type: none"> ● Promote and support research initiatives by existing research centres and government bodies. 	

1 (c) Critically monitor the development and implementation of National Standards of care for people with disabilities

<ul style="list-style-type: none"> ● We are parents/ family of people with disabilities and/or autism. 	<ul style="list-style-type: none"> ● Critically analyse 'Standards' in development. 	<ul style="list-style-type: none"> ● To ensure that our proposals in respect of the Residential Standards, currently at consultative stage, are implemented.
<ul style="list-style-type: none"> ● We have imbedded experience of critiquing legislation and standards and working with state organisations in a consultative manner. 	<ul style="list-style-type: none"> ● Promote the development of appropriate 'Standards'. 	<ul style="list-style-type: none"> ● To secure the extension of standards of care to all other services.
	<ul style="list-style-type: none"> ● Press for the resources required to underpin the implementation of the standards. 	<ul style="list-style-type: none"> ● The timely implementation of the standards.

Inputs	Activities/Strategic Objectives	Medium Term Outcomes
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1 (d) We try to affect societal attitudes to disability; in particular the “charity” model of care as opposed to a rights based model.

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| <ul style="list-style-type: none"> ● We are parents/ family of people with disabilities and/or autism. | <ul style="list-style-type: none"> ● Educate our members about the differing concepts of 'caring models', e.g. 'charity/medical', 'social' and 'rights based'. | <ul style="list-style-type: none"> ● Prepare a policy document on alternative models of care. |
| <ul style="list-style-type: none"> ● We have an acquired knowledge at executive level of the differing models of caring and their implications. | <ul style="list-style-type: none"> ● Promote an understanding of the negative effects of the 'charity/medical' model extant in Ireland and an awareness of the need to move towards a 'social/rights based' model. | <ul style="list-style-type: none"> ● Re-engage the media at a national and local level. |
| <ul style="list-style-type: none"> ● We have access to the major disability research centres in Irish Universities. | <ul style="list-style-type: none"> ● Facilitate the training of parents for the media. | <ul style="list-style-type: none"> ● To have sourced a media resource available for our members. |

2. INFORMATION ADVICE AND SUPPORT

The NPSA is committed to achieving its aims through informing and supporting its members and further by providing a resource for the public generally with a view to promoting greater awareness and understanding of issues affecting people with disabilities. Targeted training for members in particular fields is essential in driving change; the NPSA sees itself as a facilitator for such initiatives.

Inputs	Activities/Strategic Objectives	Medium Term Outcomes
2 (a) Communication & Information		
<ul style="list-style-type: none"> ● Technology support and expertise from NPSA members. 	<ul style="list-style-type: none"> ● To ensure that the website is up to date and as relevant as possible. 	<ul style="list-style-type: none"> ● To have secured resources to facilitate the regular update of the website content.
<ul style="list-style-type: none"> ● Existing executive experience of producing the newsletter. 	<ul style="list-style-type: none"> ● Use the newsletter as a medium for informing and provoking debate. 	<ul style="list-style-type: none"> ● To have secured resources to facilitate the development of the website facilities including an online interactive forum. ● To have secured the resources for the quarterly production of the newsletter. ● Expand the newsletter content to include contributions from member and other relevant parties.
<ul style="list-style-type: none"> ● Executive experience of producing informative DVDs on focused topic areas.. 	<ul style="list-style-type: none"> ● Prepare an information booklet on basic rights and entitlements. 	<ul style="list-style-type: none"> ● Develop the newsletter to include once off special editions. ● To have available a booklet on basic rights and entitlements updated annually.

Inputs	Activities/Strategic Objectives	Medium Term Outcomes
	<ul style="list-style-type: none"> ● To promote an understanding of specified aspects of intellectual disability and/or autism at conferences, in schools and other for a. ● To advance understanding and enhance knowledge of disability through the production of media based material. 	<ul style="list-style-type: none"> ● Expand the schools talks and conference contributions by increasing the involvement of NPSA members in the service. ● Secure resources for the production of media based material (e.g. DVDs etc) to advance understanding and enhance knowledge of disability.

2 (b) Advocacy & Support		
<ul style="list-style-type: none"> ● Informal individual advocacy and support has always been provided by executive members to date. 	<ul style="list-style-type: none"> ● To support members through advice and listening and advocacy. 	<ul style="list-style-type: none"> ● To have available for members a telephone based facility for support through advice and listening.

3. MEMBERSHIP, FUNDING & ADMINISTRATION

Fundamental to the NPSA is its membership base. The membership base requires active management to consolidate and expand membership in order to ensure the voice of the NPSA is reaching as many as possible, is informed by its members and remains relevant to the lives of people with disabilities and autism.

One of the key challenges for any voluntary organisation is maintaining an adequate resource base in order for it to achieve its objectives. This is no different for the NPSA and four sources of funding support are identified as essential for the continuance of NPSA activities. Further the NPSA believes that it is essential to achieve the right balance of employed and voluntary input; without an active voluntary involvement the organisation can become detached from those it has set out to represent.

Inputs	Activities/Strategic Objectives	Medium Term Outcomes
3 (a) Membership		
<ul style="list-style-type: none"> ● A strong membership with continuous executive involvement since the inception of the organisation. 	<ul style="list-style-type: none"> ● Consolidate the existing membership base through good communication and active member involvement. ● Expand the membership base particularly outside of existing areas of strong membership through enhanced local meetings and information distribution. 	<ul style="list-style-type: none"> ● Have members involved in all aspects of the organisations activities, participating in committees and representing the NPSA in public fora. ● Have active member groups and individual members throughout the country.
3 (b) Resources		
<ul style="list-style-type: none"> ● Executive expertise in administration and finance. 	<ul style="list-style-type: none"> ● Achieve the most effective balance of paid and voluntary personnel to include an Executive Director, voluntary Executive Members and an administrative assistant. 	<ul style="list-style-type: none"> ● Have agreed amended terms, conditions and job description of the Executive Director.

Inputs	Activities/Strategic Objectives	Medium Term Outcomes
<ul style="list-style-type: none"> ● Executive experience in running a voluntary organisation in the disability sector. 	<ul style="list-style-type: none"> ● Secure the required financial resources to underpin the objectives and strategy of the NPSA through: <ul style="list-style-type: none"> - Members contributions - Funding from state bodies - Philanthropic and corporate contributions - Fees for services ● Secure appropriate operating facilities. 	<ul style="list-style-type: none"> ● Have recruited and agreed terms, conditions and job description of a part-time administrative assistant. ● Have secured agreement for a restructuring of the members subscriptions in accordance with the Members Subscriptions Review - 2008 ● Have identified and secured project funding from relevant state agencies and schemes (i.e. National Lottery, Dormant Accounts) etc.). ● Have achieved the target donations from philanthropic and corporate contributors. ● Have an agreed level of fee to be charged for Conference and other contributions by Executive Members. ● Have secured appropriate office capacity.

Inputs	Activities/Strategic Objectives	Medium Term Outcomes
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3 (c) Organisational structure

<ul style="list-style-type: none"> • Executive expertise in administration and finance. • Executive experience in running a voluntary organisation in the disability sector. 	<ul style="list-style-type: none"> • Complete corporate restructuring of the NPSA 	<ul style="list-style-type: none"> • NPSA restructured as an Un-limited Company. • Charitable status secured.
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Director and Executive

Seamus Greene

Director

Seamus is a founder member of the NPSA and was its first chairperson. In 2003 he became the first Director appointed by the Alliance. He was a member of the 'Disability Legislation Consultation Group' and the 'Department of Health and Children Monitoring Committee' on services for people with intellectual disability and autism. He played a key role in the direction and coordination of the national campaign for improvements in the Disability Act 2005. He was also instrumental in producing Imagine What it's Like, a DVD for teachers on Aspergers Syndrome and Autism. He has thirty three years experience as a second level teacher and school principal.

Mary Allen

Executive Member

Mary has been a member of the NPSA since 2002. She is a founder member and secretary of Parents & Friends of People with Special Needs, Fermoy, and Secretary of the local branch of the Cope Foundation Committee. She currently co-ordinates a Community Service Programme for older people within a LEADER company.

Brid Cole

Executive Member

Brid is the parent of a forty year old man with Down Syndrome and has over the course of the past thirty years engaged in numerous campaigns as a member of a number of representative organisations. In that time she has been involved with Down Syndrome Ireland, Inclusion Ireland and the parent groups attached to the service providers her son has attended. She has been on the NPSA executive for the past three years

Frank Conaty

Executive Member

Frank has been a member of the NPSA since 2000 and has been on the executive for the past three years. He has been a member of the Brothers of Charity Galway Council and was a founding member of the Galway Alliance of Parents & Carers (GAP). Frank lectures at NUI Galway and is an academic member of the Centre for Disability Law & Policy research.

Geraldine Graydon

Executive Member

Geraldine was a founding member of the Autism Life-Care Trust and was a member of the National Parents Council – Primary. Geraldine in her work with REHAB Ireland is a coordinator of the Partners in Policy Making movement and has been an executive member of the NPSA for the past three years.

Tom Healy
Executive Member

Tom has been an activist in the disability sector for over two decades serving on numerous committees and boards. He is currently a board member of Inclusion Ireland and is chairman of Connemara Parents & Friends. Tom has been a member of the executive of the NPSA since its foundation.

Kieran Kennedy
Executive Member

Kieran Kennedy is the CEO of the Irish Progressive Association for Autism (IPAA). It was set up in September 2001 by a handful of concerned parents of Autistic children who were unable to secure appropriate services for their children. Kieran was a founder member of the association. Since then he has devoted practically all of his time towards the provision of advice and services to families affected by Autism. Kieran has strong links with the Health Service Executive and the Department of Education.

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