
Scoping study for a National Intellectual Disability Advocacy Initiative

A Report for Genio

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Executive Summary

This report was commissioned by Genio with the following terms of reference

1. Describe the key features of a National Intellectual Disability Advocacy Initiative;
2. Outline an appropriate approach to developing such an initiative based on a clear identification of strengths that could be built upon in an Irish context, and learning from other countries;
3. Identify the costs of establishing and running such an initiative for the first three years.

The authors consulted with key stakeholders and informants, and undertook a literature review, which included the collection of information on similar initiatives in other jurisdictions.

In making the case for a National Intellectual Disability Advocacy Initiative (NIDAI), it is asserted that as human beings and as citizens, people with intellectual disabilities share the instinct and right to express themselves, to be heard, and to exercise control over their lives. However, in practice, too few experience the opportunity to have real control over their lives, while their voices are too often restricted or silenced. Empowering them, then, involves identifying and addressing the various barriers that compromise the self-determination aspirations of people with intellectual disabilities – effectively, that deny them their civil and human rights. It also involves exploiting the various environmental opportunities and assets that currently exist and which suggest that a self-advocacy initiative may be timely and opportune.

In exploring the wider context of self-advocacy, it is seen how claiming one's voice has been shown, in other arenas, not just to have a profound effect on the individual but on services and the wider system. A number of policy and legislative changes, both recent and anticipated, have the potential to reframe current disability policy towards a system of supports that enable active citizenship and independence – including a system of individualised funding to underpin the provision of supports and to provide greater control and choice to the person and their family. Similarly, the proposed Mental Capacity Bill is founded on a presumption of capacity and will require that the person be permitted and encouraged to participate as fully as possible in any act done on their behalf or in any decision affecting them. These changes highlight the need for individuals to be supported to develop the necessary skills to advocate on their own behalf, or to have independent advocates who will act in their best interests.

International instruments that support such policy and legislative shifts include the UN Convention on the Rights of People with Disabilities and the Council of Europe

Disability Action Plan. Also, the development of advocacy services and supports in other arenas in Ireland similarly point to the potential of an initiative for people with intellectual disabilities. This potential is echoed in the substantial and growing literature on advocacy – which serves also to differentiate the various forms of advocacy and to consider their potential and their limitations – and in examples of self-advocacy initiatives in other jurisdictions.

The consultative interviews undertaken for this study elicited broad support for NIDAI as a worthwhile initiative and contributed helpful and insightful advice as to how it might be framed and developed. This includes the perspective that supporting people with intellectual disabilities to claim their voice should be seen as a civil rights, rather than disability, issue; the initiative should be independent; controlled by people with intellectual disabilities; and should be realistic in the pace of its development.

Drawing on important insights from the literature review – including desk research on established self-advocacy models in other jurisdictions – and the consultative meetings with key stakeholders and informants, we identify important elements to feature in NIDAI’s design. We acknowledge that the establishment of such an initiative will need to be catalysed by a combination of activists and funders while setting specific targets for the achievement of the endorsement, engagement and active participation of people with an intellectual disability. This would enable it to be credibly considered a self-advocacy movement within a 3 to 5 year period.

The leadership of the initiative should transition within this timeframe to a Board comprising up to ten people with intellectual disabilities, supported by independent “allies” whose sole role is to support them in achieving their goals. We consider that the leadership should emerge through a process of consultative meetings with people with intellectual disabilities around the country, rather than being selected by the activists-initiators. NIDAI will employ staff and will offer both individual and group advocacy. The role of citizen advocacy, particularly for people who have difficulty in articulating their needs and wishes, needs to be considered further.

In considering various options for the establishment of NIDAI we conclude that it would be prudent, in its early years, to seek a hosting arrangement with an established organisation to provide administrative and other organisational supports while it is focusing on establishing its mission, membership and profile. There is a compelling argument to seek such alignment with an organisation that is in the mainstream and that is focused on issues of human rights, citizen participation and equality – rather than one that is exclusively identified with disability. We have identified a hosting arrangement with the Irish Human Rights Commission as the ideal, but consider the Citizens Information Board as an attractive alternative.

The establishment of NIDAI will require initial funding from government or philanthropy, or preferably both. As it develops, it will need to broaden its income base and we believe that a combination of membership fees, earned income, contributions from service providers and the establishment of a community foundation – in addition to continuing philanthropic and public support – represent realistic and achievable pathways towards sustainability.

Drawing together its different features, we describe a positive vision of NIDAI as it might look in 2014 and in 2021, in particular, that it will operate with people with intellectual disabilities at its core, giving leadership through their participation at all levels of the initiative and determining its key decisions and activities, with the support of volunteer allies and key staff.

We suggest the appointment of a Steering Group with specific terms of reference to establish the initiative and a number of further initial steps towards making NIDAI a reality. Finally we estimate that a budget of €500,000 over the first three years would be adequate to support NIDAI through its development phase. Thereafter, it is likely that costs will rise as further staff are added, leading to increased activity levels and as communications and other externally focused functions are developed.

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1. Introduction

1.1 Background to Genio

Genio is designed to act as a resource to key stakeholders by providing specific supports to assist in the implementation of national policy to bring about real and long-lasting improvements in the lives of people with disabilities and mental health difficulties. This is done in three ways;

1. By providing **financial support** in the form of relatively small grants which are aimed at providing stimulus funding to support change;
2. Through **capacity building** initiatives aimed at diverse audiences including service users and families, service providers and policy makers;
3. By **providing and disseminating evidence** on individual outcomes and the cost-effectiveness of individualised supports and services in an Irish context, and on the processes and structures that are efficient and support good outcomes.

1.2 Background to this report

In the course of the work that Genio has conducted over the last number of years it has become clear that there is a need for the establishment of a National Intellectual Disability Advocacy Initiative (NIDAI) that would strengthen the voice of those with intellectual disabilities. Unlike the mental health area which has a National Service User Executive (NSUE) there has been no such development in the intellectual disability area. While there are organisations advocating for improvements in services, they are not doing so from a service user perspective *per se*. Inclusion Ireland has carried out developmental work on a national self-advocacy forum which has helped to build capacity (see Section 3.5). There are also many small, local self-advocacy groups around the country although most of these groups are organised and facilitated by service providers and do not have a national reach¹. These groups could be usefully involved in a national self-advocacy initiative and may well be the source of potential leaders and participants. There is also a need to ensure the interests of those whose capacity precludes them from speaking on their own behalf are adequately and appropriately represented. An initiative such as the National Intellectual Disability Advocacy Initiative could include independent citizens who could be involved in helping to represent the interests of these individuals.

¹ Lundstrom, F. (2008) *Mapping Self-Advocacy Initiatives for People with Intellectual Disability in Ireland*. Dublin: Comhairle

1.3 Terms of reference

Genio commissioned a scoping study to identify the best approach to developing a National Intellectual Disability Advocacy Initiative² (NIDAI). The key tasks of the scoping study were to:

1. Describe the key features of a National Intellectual Disability Advocacy Initiative;
2. Outline an appropriate approach to developing such an initiative based on a clear identification of strengths that could be built upon in an Irish context, and learning from other countries;
3. Identify the costs of establishing and running such an initiative for the first three years.

1.4 Approach

Owen Keenan, Consultant, and Fiona Keogh, Research and Information Manager, Genio, consulted with key stakeholders and informants in this area. A literature overview was also conducted which included the collection of information on similar initiatives in other jurisdictions.

This report firstly presents the case for a National Intellectual Disability Advocacy Initiative (Chapter 2) and then goes on to describe the wider context for this initiative (Chapter 3). The findings of the literature review (Chapter 4), from other jurisdictions (Chapter 5), and from the consultation (Chapter 6) are presented, leading to a description of the features of a National Intellectual Disability Advocacy Initiative (Chapter 7) and the first steps that may be taken to establish such an initiative (Chapter 8).

² The acronym NIDAI will be used to describe the proposed initiative for the purposes of this report. Finding an appropriate and permanent name for the initiative will be a task for those who will be involved in establishing and running the organisation.

2. The case for a National Intellectual Disability Advocacy Initiative

In articulating the problem that a self-advocacy initiative for people with intellectual disabilities might seek to address, it is important to begin with the assertion that having a sense of control over our lives, and the opportunity to be self-determining, is central to our understanding of what it is to be human, and of our participation in society as citizens. Although the opportunity to be fully self-determining is tempered by our education, income, opportunities, social norms, how society is structured, etc., most of us have the opportunity for self-actualisation within these constraints. It is indicative of the centrality of the capacity to control our lives that it is the loss of this freedom – rather than any other punishment – that is at the heart of our prison system, for those that have stepped outside the law and (temporarily) lost their right to participate in society.

Both as human beings and as citizens, people with intellectual disabilities share the instinct and the right to express themselves, to be heard, and to exercise control over their lives. We are all limited in our capacities and opportunities to realise full self-determination and it has to be recognised that having an intellectual disability can be a real and significant constraint, but it does not exclude the capacity to express oneself in every facet of one's life. Unfortunately, in too many instances, the fact of having an intellectual disability also results in a loss of opportunity to express one's wishes, desires and requirements in areas where one does have capacity. In short, too few people with intellectual disabilities experience the opportunity to exercise real control over their lives, while their voices are too often restricted or silenced.

Although the rights of people with intellectual disabilities are recognised in legislation and policy, in practice they experience major difficulties in exercising them. They are frequently marginalised; they are excluded from decisions – both large and small – that affect their lives; a good deal of what passes as consultation is tokenistic in reality; while they are denied many of the opportunities to participate in society that most of us take for granted as citizens. It matters little that the motivation behind such denial of rights is generally well-intentioned – an instinct to safeguard and protect, to prevent the person with an intellectual disability from doing the “wrong” thing, from making the “wrong” decision. But how would we feel if, every time we were on the brink of doing or deciding something for ourselves, somebody else stepped in and did, or decided, it on our behalf?

It could be argued that the basis of such intervention in the lives of people with intellectual disabilities makes addressing it more difficult and sensitive. Empowering people with disabilities to have more control over their lives effectively means, for many, shifting the balance of power between them and their parents and/or siblings,

so clearly there is considerable potential for hurt and distress in achieving this change. But siblings and parents are also significant potential allies in addressing the other barriers that people with intellectual disabilities encounter in attempting to exercise more control over their lives.

These barriers are many and complex but include:

- Historically negative perceptions of people with limited intellectual capacity and the practice of placing them in institutions, thereby excluding them from society. Although policies and provision have changed significantly in recent decades, it is important to acknowledge that many of us continue to hold some vestiges of the attitudes and perceptions towards people with intellectual disabilities from our socialisation as children. For example, a study by the National Disability Authority found that 29% of a representative sample of the adult Irish population thought that children with intellectual disability should not attend the same schools as children without disabilities and 8% would object if such a child was in the same class as their child³.
- Policy and service provision to people with intellectual disabilities have focused primarily on a deficit model, emphasising primarily what the person cannot do, rather than what their abilities are. This is amplified by a dominant focus on their vulnerability to a range of risks and a perception of society as risk-averse.
- The fact that intellectual disability – as other disabilities – has been defined in terms of illness, and this has led to the dominance of the medical model as the basis of intervention in terms of both policy and service provision.
- The prevailing intellectual disability structures – from government departments through statutory agencies and non-statutory networks, service providers and parent and sibling groups – has served to exclude people with intellectual disability from having any input of significance. In particular, in the development of policy and services, more attention and credence has been given to the interests of service providers and professional disciplines than has been given to people with intellectual disabilities or their representatives.
- The reality of an intellectual disability as a barrier to full expression also needs to be acknowledged – although each specific disability should be seen in terms of its impact on the life of the individual person, rather than be generalised across the entire cohort of people with intellectual disabilities. For some, their intellectual disability is compounded by speech and language difficulties that further impede their capacity to articulate their needs, interests and wishes.
- The complexities of the relationships that adults with intellectual disabilities have with their parents and siblings need to be acknowledged – while also recognising that frequently families represent the only advocates the person with the intellectual disability has.

³ National Disability Authority (2007) *Public Attitudes to Disability in Ireland*. Dublin: NDA

- Although the multi-annual investment plan that accompanied the National Disability Strategy injected substantial funds into the disability sector, these funds were not sufficiently aligned with the policy objectives of Towards 2016⁴. Consequently people with intellectual disabilities have not benefitted, to the extent that they might otherwise have done, from opportunities to develop their capacities to the full, or to avail of supports and resources – including independent advocacy – that would facilitate a more independent and self-determining lifestyle within communities.

These are very real barriers that continue to compromise the self-determination aspirations of people with intellectual disabilities. Mostly they are features that have persisted over several decades, at least, and they will not easily be overcome. Nevertheless the coherent and strategic development of an initiative to promote and support self-advocacy by people with intellectual disabilities may be both timely and opportune, due to the combination of a number of positive factors in the current environment. These include:

- The significant national disability policy shift towards a person-centred approach reinforced by the proposed development of congruent funding models;
- The preparation of the Mental Capacity Bill which, if passed, will have major significance – particularly in its presumption of capacity unless there is evidence to the contrary;
- The context of developing initiatives and experience in self advocacy by people with mental health issues and physical and sensory disabilities;
- Developing experience in self-advocacy internationally including the availability of substantial literature on the subject – augmented by access to a growing international community of self-advocates, activists and academics;
- The opportunity to use international instruments such as the UN Convention on the Rights of People with Disabilities as a basis and framework for the development of self-advocacy in Ireland;
- The opportunity to engage parents and siblings as allies in promoting self-advocacy through demonstrating that it is beneficial both to the person with an intellectual disability and to families.

2.1 Summary

Everyone has a fundamental need to feel in control of their own life, to have their own voice in articulating their needs, wishes and interests. Too many people with an intellectual disability are limited in the extent to which this is realised – not only due to the constraints of their disability, but because of history, attitudes and a range of

⁴ Department of the Taoiseach (2006) *Towards 2016: Ten Year Framework Social Partnership Agreement 2006-2015*. Dublin: Stationery Office

other barriers that they invariably encounter in their external environment. In short, people with intellectual disabilities experience, to varying degrees, a denial of opportunity for self-actualisation and full participation in society according to their abilities. It is this denial of their civil and human rights that a self-advocacy initiative would seek to address. In designing such an initiative it is essential that the extent and nature of the barriers they encounter, and of current environmental assets and opportunities, are fully understood.

This report describes the wider national and international context for such an initiative, and draws together the findings from a literature review, the learning from key informants in the sector and the experience from other jurisdictions to describe the features the NIDAI might have and the initial steps that could be taken to establish such an initiative.

3. Wider context

Advocacy is "...a necessary measure to give voice to the voiceless and to ensure that people with disabilities can have a direct say in all matters that affect their own personal destiny ... advocacy is a key factor in advancing the autonomy and independence of persons with disabilities. These goals are not merely desirable in themselves. They flow from the basic rights that we all share in common as human beings." (p.v)⁵

Donal Barrington President, Irish Human Rights Commission (2001)

Having one's voice heard is a defining element of citizenship and is therefore highly cherished by all members of society. It finds formal expression in the casting of a vote when electing representatives and finds everyday expression in the myriad of decisions we make each day in the course of our lives. The opportunity to make decisions, express our views, opinions and wishes and therefore to be autonomous individuals is not ordinarily available to many Irish citizens, particularly those with intellectual disability.

Having one's voice heard is not just a fundamental right. The claiming of voice by individuals in many sectors such as mental health, physical disabilities, children and older people, has been shown to have a profound effect, not just on the individual, but on services and the wider system. The Centres for Independent Living (CILs) that emerged in Ireland in the '80s and '90s were run by people with physical disabilities for people with physical disabilities and their aim was to empower and enable people with disabilities to achieve Independent Living, choice and control over their lives and full participation as equal citizens in society. There are now 23 CILs in Ireland providing an independent living alternative to residential care that was not previously widely available. In mental health, the Irish Advocacy Network has grown from a small group of self-advocates to a provider of peer-advocacy services in almost all acute mental health units in Ireland. Service users now participate in mental health services management groups and in planning and designing mental health services. The value of 'experts by experience' is now recognised in universities where such experts are employed as part of the education of health professionals. The recently established National Service User Executive is a representative body for all mental health service users. People with mental health difficulties or physical disabilities are now routinely involved in policy-making and other bodies and are regularly consulted in decisions regarding service development and management.

However, there is one group that have yet to claim their voice in the same way – people with intellectual disability. Having one's voice heard is not an easily exercised right for some. People with intellectual disability can face particular challenges in

⁵ Forum of People with Disabilities (2001) *Advocacy: A Rights Issue*

articulating their needs and wishes directly. For those with little or no verbal communication the challenges are even greater. Most of these individuals live in closed environments; over 4,000 people with intellectual disability live in congregated settings; over 16,000 attend segregated day settings, and live out their lives with little or no access to independent advocacy and little opportunity to speak for themselves.

3.1 Policy and legislative context

One of the first times the voice of people with disabilities was heard in a national context was in the course of the consultation process that informed the Commission on the Status of People with Disabilities. This Commission was established in 1993 to advise the government on *“the practical measures necessary to ensure that people with disabilities could exercise their rights to participate, to the fullest extent of their potential, in economic, social and cultural life”*⁶. A detailed consultation process informed the wide-ranging recommendations of the Report of the Commission. This was the first time people with disabilities and their families were consulted in such detail as it was recognised that they were best placed to tell their story and to voice their needs and wishes. The expression of marginalisation that emerged from this consultation provoked a series of actions based on the recommendations of the Report. The Equality Act (2004, which amended the Employment Equality Act 1998 and the Equal Status Act 2000) enshrined rights for all citizens and outlawed discrimination on the basis of disability (and eight other grounds).

3.1.1 New policy proposals

A review of the efficiency and effectiveness of Disability Services funded from the Health Vote is currently underway, as part of the Government’s Value for Money (VFM) and Policy Review Initiative. As part of this process, an Expert Reference Group was established to review current policy in relation to disability services. The key themes emerging from the review were recently published⁷. The policy proposals envisage the person with a disability as a self-determining citizen and propose a range of supports and services required to realise this vision. Central to this vision is the reframing of current disability service provision from services which act to keep the person as passive and dependent towards a system of supports which enable active citizenship and independence. Individualised supports are proposed, which include a range of assistance and interventions required to enable the individual to live a fully included life in the community. An important feature of supports is that they will be tailored to the needs of the individual and determined and directed by the person, with support if necessary. A system of individualised funding is also proposed to underpin the provision of individualised supports and to provide greater

⁶ Report of the Commission on the Status of People with Disabilities (1996) *A Strategy for Equality*. Dublin: The Stationery Office p.iii

⁷ http://www.dohc.ie/publications/pdf/key%20themes%20paper_summary2010.pdf

control and choice to the person and their family. These proposals highlight the need for individuals to be supported to develop the necessary skills to advocate on behalf of themselves, or to have independent advocates who will act in their best interests.

3.1.2 Mental Capacity Bill

The Mental Capacity Bill⁸ is another important element of the policy landscape that will facilitate the development of a National Intellectual Disability Advocacy initiative. The Capacity Bill proposes a fundamental change from existing law on what constitutes lack of capacity and is central to the reform of this area. The focus in the Capacity Bill will be on the particular time when a decision has to be made and on the particular matter to which a decision relates, not on any general review of capacity to make decisions generally⁹. The announcement from the Minister for Justice noted that *“this is a significant change from the current system, where a finding of incapacity applies to every decision a person may make and every legal transaction they may wish to enter into. In line with international best practice, as well as a recommendation of the Law Reform Commission, capacity will be understood as the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made. ...The person must, so far as is reasonably practicable, be permitted and encouraged to participate, or to improve his or her ability to participate, as fully as possible in any act done for him or her and any decision affecting him or her. This first step is assisted decision making. The next step would be substitute decision making, whether by the court or by a personal guardian appointed by the court. ...The Bill will enable the State to meet its obligations under the United Nations Convention on the Rights of Persons with Disabilities, signed by Ireland on the 30th March 2007, in relation to legal capacity issues”*¹⁰.

3.2 International context

The Convention on the Rights of Persons with Disabilities¹¹ (CRPD) provides a supportive international context for self-advocacy and national representation for people with disabilities. The CPRD is an international human rights instrument of the United Nations which aims to “promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities”¹². It covers a number of key areas such as accessibility, personal mobility, health, education, employment, rehabilitation, participation in political life, and equality and non-discrimination.

⁸ Government of Ireland (2008) Mental Capacity Bill. Dublin: Stationery Office

⁹ Minister Ahern announces proposals for a Mental Capacity Bill, September 2008, <http://www.justice.ie/en/JELR/Pages/Minister%20Ahern%20announces%20proposals%20for%20a%20Mental%20Capacity%20Bill>

¹⁰ Ibid 2008

¹¹ United Nations (2006) *UN Convention on the Rights of Persons with Disabilities*. Geneva: United Nations

¹² National Disability Authority, *UN Convention on the Rights of People with disabilities and the Council of Europe Disability Action Plan*. Dublin: NDA. p.5

General principles of the Convention include respect for *“individual autonomy including the freedom to make one’s own choices, and independence of persons”* and *“full and effective participation and inclusion in society”*¹³.

In the area of freedom of expression and opinion and access to information, the Convention requires that appropriate measures are taken to ensure that persons with disabilities can exercise the right to freedom of expression and opinion (Article 21). In terms of participation in political and Article 29, public life, states the Convention requires that persons with disabilities shall be guaranteed political rights and the opportunity to enjoy them on an equal basis with others, which includes:

- (i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
- (ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

Adopted by the Council of Europe in April 2006, the Disability Action Plan 2006-2015¹⁴ seeks to *“translate the aims of the Council of Europe with regard to human rights, non-discrimination, equal opportunities, full citizenship and participation of people with disabilities into a European policy framework on disability for the next decade”*. The Action Plan shares similar governing principles to the UN Convention and contains a number of specific actions, including participation in political, public and cultural life, education, information and communication, employment, accessibility of the built environment and transport. Member States are recommended to integrate the actions set out in the Action Plan into their policy, legislation and practice in order to promote the rights and full participation of people with disabilities in society.

The Convention and the EU Disability Action Plan mark a shift in thinking about disability from primarily a welfare concern to a human rights issue. The requirements around full and effective participation in society, specifically in terms of representation and freedom of expression are very clear. However, while people with mental health difficulties and physical disabilities have organisations to represent themselves, or can represent themselves as individuals, people with intellectual disability do not currently have such a forum.

This new national policy context, along with the Capacity Bill and the international framework of the UN convention, indicates a supportive environment for the

¹³ Ibid. United Nations (2006)

¹⁴ Council of Europe (2006) *Disability Action Plan 2006-2015*.
http://www.coe.int/t/e/social_cohesion/soc-sp/integration/02_Council_of_Europe_Disability_Action_Plan/

development of an initiative such as the National Intellectual Disability Advocacy Initiative.

3.3 The Citizens Information Board

In Ireland, The Citizens Information Board (CIB, formerly Comhairle) is responsible for supporting the provision of information, advice and advocacy on a wide range of social and civil services. CIB is governed by the Citizens Information Act 2007, and the Comhairle Act 2000. The mandate of the CIB, as defined by the Acts, is:

- To ensure that individuals have access to accurate, comprehensive and clear information relating to social services;
- To assist and support individuals, in particular those with disabilities, in identifying and understanding their needs and options;
- To promote greater accessibility, coordination and public awareness of social services;
- To support, promote and develop the provision of information on the effectiveness of current social policy and services and to highlight issues which are of concern to users of those services;
- To support the provision of, or directly provide, advocacy services for people with a disability.

A new National Advocacy Service has been set up to provide independent, representative advocacy services for people with disabilities¹⁵. It is organised and managed on a regional basis by five Citizens Information Services and is supported by the Citizens Information Board. Each team will have a regional manager, a senior advocate, an administrator and between five and seven advocates. From January 2011 the new Service has taken over the work of the 46 pilot advocacy projects, with a particular remit for more vulnerable people with disabilities.

3.4 Developments in other sectors

There are several organisations which represent people with different vulnerabilities in other sectors, many of which were established and are run by self-advocates.

3.4.1 Mental health

The Irish Advocacy Network (IAN) is a service user organisation which was founded in 1999 with the aim of developing the process of peer advocacy in mental health in Ireland. The IAN developed slowly from an initial national conference, and there are now 23 full time advocates who visit all acute mental health units in Ireland providing support and information to inpatients, particularly those who are involuntarily detained.

¹⁵ http://www.citizensinformationboard.ie/services/advocacy_services/

IAN also offers peer advocacy training, volunteer training, and user-support meetings. Other services offered by the IAN include mental health awareness training and strategic planning, monitoring and evaluation.

*A Vision for Change*¹⁶, the report of the Expert Group on Mental Health Policy, recommended the establishment of a National Service Users Executive (NSUE) to inform the HSE, the Mental Health Commission and other bodies, 'on issues relating to user involvement and participation in planning, delivering, evaluating and monitoring mental health services and to develop and implement best practice guidelines between the user and provider interface including capacity development issues'¹⁷.

The NSUE was established in 2007 on an interim basis and was fully incorporated in 2008. The inaugural conference was held in January 2009 and elections have been held for representatives. The central objective of the NSUE is 'to provide an effective, independent, representative structure through which all people with poor mental health and severe emotional distress and their families and/or carers, can participate in and influence decision making which impacts on the lives and opportunities of such people'¹⁸.

3.4.2 Children

EPIC – Empowering Young People in Care (formerly the Irish Association of Young People in Care) is an independent association that works with and for children and young people who are currently living in care or who have had an experience of living in care. This includes those in residential care, foster care, hostel, high support & special care. EPIC also works with young people preparing to leave care and in aftercare¹⁹.

EPIC has been set up to:

- Give a voice to what young people with care experience are saying
- Explain the rights of young people in care
- Give information, advice and support to young people with care experience
- Help people who work with young people in care to involve them more when decisions are being made about them.

Young people are on the board of the EPIC and take part in groups to consult on various issues.

¹⁶ Department of Health and Children (2006) *A Vision for Change: Report of the Expert Group on Mental health Policy*. Dublin: Stationary Office

¹⁷ <http://www.nsue.ie/>

¹⁸ <http://www.nsue.ie/>

¹⁹ <http://www.iaypic.org/index.php>

3.4.3 Older people

Older & Bolder is an alliance of eight non-governmental organisations that champions the rights of all older people, and seeks to combat ageism, acting as a catalyst for²⁰:

- Supporting older people, through its member organisations, as active participants in shaping an Ireland that promotes the welfare and quality of life of all citizens;
- Positively influencing and shaping beliefs and values, attitudes and opinion regarding ageing and older people;
- Valuing the role of older people in the community and understanding the diversity of older people, including those with a disability;
- Promoting an age-friendly society where decisions are informed by the expressed needs and preferences of older people and evidence-based research.

3.4.4 People with sensory disabilities

Deafward is the advocacy service provided by the Irish Deaf Society. Deaf advocacy means *'taking action to support Deaf people, to say what Deaf people want, protect their rights, stand for their interests and to insure they have access to services they need'*²¹. *Deafward* undertakes the following actions:

- Establishes and develops contacts with Deaf clubs/meetings nationwide to provide information through ISL and collect deaf people's comments;
- Attends meetings, conferences, and workshops to make sure there is an awareness of what deaf people's needs are;
- Provides training to develop deaf people's personal and social skills so they can feel part of their community. This would also increase self confidence with independence in life to make their own decisions;
- Builds Community Networks through Irish Sign Language.

3.4.5 Cross-disability advocacy organisations

People with Disabilities in Ireland (PwDI) is a national organisation that was created *'to provide an effective, representative structure through which all people with disabilities, their parents, partners, relatives, carers and organisations of people with disabilities can participate in and influence decision-making which impacts on the lives and opportunities of people with disabilities'*²².

PwDI aims to support all people with disabilities to take part in and influence the decision making process that impacts on their lives and opportunities; *'PwDI is for all people with disabilities, whether those disabilities are physical, emotional, intellectual or mental'*. Parents, partners, carers and groups of people with disabilities can also

²⁰

²¹ <http://www.irishdeafsociety.ie/>

²² <http://www.pwdi.ie/>

join PwDI. Members form network committees in each county, nominate board representatives and employ a national office to carry out policy enacted by the national board.

3.5 Self-advocacy groups in intellectual disability

Inclusion Ireland has undertaken considerable work in developing a national forum for people with intellectual disability. This has mainly involved building capacity at local level through supporting the development of self-advocacy groups where there were no such groups and encouraging and building skills in established self-advocacy groups. Thus there currently exists a considerable number of local groups, many with skilled members who could potentially play a leadership role at national level. Inclusion Ireland also held a national conference to bring interested parties together and begin the process of developing a national forum. However, personnel changes in Inclusion and a lack of dedicated funding have hampered the further development of this initiative.

The CIB commissioned a mapping study of self advocacy initiatives for people with intellectual disability in Ireland which has been published in 2008²³. Eighty seven service providers were surveyed about initiatives *that may facilitate self advocacy* (a very broad definition) and forty three organisations responded reporting the following self-advocacy initiatives:

Self advocacy training	79%
Person-centered planning	93%
Council on Quality and Leadership	39%
Other initiatives encouraging autonomy	58%

No single figure was given as the number of self-advocacy initiatives in intellectual disability services as there was overlap in different categories. However, 34 organisations provide self-advocacy training, and this number is used here as an indicative total. Specific information on the type of self advocacy initiatives that are currently taking place in some intellectual disability services was requested, and the number of organisations involved in these, are shown in Table 1 below.

²³ Lundstrom, F. (2008) *Mapping Self-Advocacy Initiatives for People with Intellectual Disability in Ireland*. Comhairle, Dublin.

Table 5.1: Type of self-advocacy initiatives in service providers (n=43)

Type of initiative	Number of organisations	Range of service users involved
Workers/service users committees	29	3-100
Workers/service users consultative group	11	2-100
Service users councils	17	2-80
Representation on decision making committees	17	1-35
Representation on Board of organisation	5	1
Representation on local consumer councils	1	1
Service users lobbying at local, national or EU level	17	3-100
Involvement in third level education	18	1-60
Other initiatives	1	5

Source: Lundstrom (2008)

Those service users who were interviewed reported significant positive changes in their lives as a result of being involved in self advocacy. An important finding was that most of those who were trained in self advocacy became a peer or group advocate within the organisation (usually in a voluntary capacity). Lundstrom notes that it may be more appropriate for those who have received this training to firstly be offered the supports to make choices about how they live all aspects of their lives, before peer advocacy is engaged in.

Lundstrom's findings describe a variety of activities that could loosely be considered 'self-advocacy' and the positive impact of these activities both for the individuals and for services. The findings also underscore the need for self-advocacy that is independent of service providers in order for individuals to make decisions and pursue courses of action that may not necessarily coincide with the interests of service providers.

Regional groups also exist. Through the South East Regional Forum on intellectual disability, a novel means of representing service users and hearing was developed called *Seasamh*²⁴. *Seasamh* is an open forum lead by a peer-elected leadership-team operating on a parliamentary basis working to improve quality of life for persons who access intellectual disability services in partnership with providers. From its inception *Seasamh* operated on a partnership basis involving 44 voluntary

²⁴ Seasamh is an Irish word meaning "Stand up"

and statutory organisations providing intellectual disability services. The work led to the development of a Certificate in Leadership and Advocacy, a third-level college course designed in direct consultation with persons facing the challenge of intellectual disability. The course has college-accreditation in three institutes.

These findings on local and regional self-advocacy groups and initiatives point to the presence of a number of people with intellectual disability who have been supported in developing the necessary skills to advocate on behalf of themselves and others. These individuals represent a cohort of people who may be interested in playing a leadership role at a national level and becoming involved in an initiative such as the NIDAI.

4. Literature review

4.1 Defining Advocacy

A widely used formal definition of social advocacy is that of Wolfensberger²⁵:

“...the functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to promote, protect and defend the welfare of, and justice for, either individuals or groups, in a fashion which strives to be emphatic and vigorous.”

This definition focuses on advocacy as the formal representation of others and fails to capture the contemporary emphasis on the empowerment of vulnerable/marginalised people. The broader concept of advocacy places the individual in the centre (“nothing about us without us”), encouraging self-sufficiency and self-determination;

“The aim of advocacy is not solely about the formal representation of others; it is equally about vulnerable people becoming empowered to become advocates in their own lives through training, education and life experience.”²⁶

The report from the Forum of People with Disabilities strongly emphasises the importance of empowerment, stating that if the representational elements and empowerments are not both in place then “...it is not advocacy” (p.8 – emphasis in original report)²⁷.

These dual components of representation and empowerment, capture central elements of advocacy today. The broad process of advocacy should reflect four main principles²⁸:

- Empowerment
- Autonomy
- Inclusion
- Citizenship.

4.2 Forms of advocacy

At least 17 different types of advocacy have been described²⁹. However there are two distinctions that are useful to consider before describing specific types of advocacy; legal versus social advocacy and individual versus systemic advocacy³⁰.

(a) *Legal versus social advocacy*

²⁵ Wolfensberger, W. Quoted in *Safeguarding Advocacy for People with Disabilities in Australia*, Judith Cook and Lorraine Zeni, Disability Advisory Council of Australia, 1993

²⁶ Forum of People with Disabilities (2001) *Advocacy: A Rights Issue* p.8

²⁷ Ibid. Forum of People with Disabilities (2001)

²⁸ Atkinson, D. (1999) *Advocacy: A Review*. Joseph Rowntree Foundation

²⁹ Ibid Forum of People with Disabilities (2001)

³⁰ Goodbody Economic Consultants (2004) *Developing an Advocacy Service for People with Disabilities*. Comhairle, Dublin.

Legal advocacy involves members of the legal profession helping individuals to exercise their rights through the courts and legal system. Legal advocacy has a significant role to play in the area of mental health, where people can be detained in hospital involuntarily. With the Mental Health Tribunals under the Mental Health Act 2001, patients are entitled to a legal representative to advocate for them through this process. Legal advocacy has also been used in the pursuance of rights for people with intellectual disability and physical disability. Social advocacy is more concerned with supporting an individual's wishes and way of life and supporting them to speak for themselves, but without the use of legal resources. There is, in reality, some overlap between the two.

(b) Individual versus systemic advocacy

Individual advocacy is focused on supporting individuals while systemic advocacy aims to influence agencies, institutions, governments and society by informing and shaping policies and legislation that may affect people with disabilities and mental health difficulties.

Self-advocacy, group advocacy and citizen advocacy are considered in more detail here as they are central to the proposed NIDAI.

4.3 Self-advocacy

A range of meanings is commonly attributed to the term 'self-advocacy', spanning personal sometimes isolated instances of 'speaking up', to the creation of formal self-advocacy groups and in some countries, national organisations³¹. Self-advocacy is the act of speaking up for oneself. This is sometimes seen as a contradiction in terms, as "advocacy" literally means 'speaking up for someone else'. In reality, self-advocacy is the process by which people are empowered to speak for themselves. Self-advocacy has been defined as;

"...an individual's ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs and rights. It involves making informed decisions and taking responsibility for those decisions"³². (p.223)

Self-advocacy has also been described as a process through which individuals represent their own needs and concerns in order to improve their own circumstances and establish their civil and human rights; and the development of skills necessary for an individual to express their views to the fullest possible extent³³. This dual aspect to self-advocacy represents a tension that can act as a barrier to successful

³¹ Tilley, L (2004) *The history of self-advocacy for people with learning difficulties: International comparisons*. Report of a conference held 6-7 May 2004, Open University, Milton Keynes.

³² Merchant D.J. & Gajar A. 1997, 'A review of the literature on self advocacy components in transition programs for students with learning disabilities'; *Journal of Vocational Rehabilitation*, Vol 8 (3), June 1997. pp. 223-231.

³³ Forum of People with Disabilities (2001) *Advocacy: A Rights Issue* p.8

development (see more detailed discussion in Section 4.5 below). The core components of self-advocacy have been identified as³⁴;

- Being able to express thoughts and feelings with assertiveness if necessary;
- Being able to make choices and decisions;
- Having clear knowledge about rights;
- Being able to make changes.

This description of the essential elements of self-advocacy highlights a central issue concerning the representation of people with intellectual disability, that is, how best to advocate for or represent those who do not have the capability (even with support and training) to do these things?

4.3.1 Features of self-advocacy

The features of a self-advocacy group have been captured very well by Downer and Ferns:

- “be independent of services and workers
- have funding without any strings attached
- be controlled by people with learning difficulties
- be advised by experienced disabled people and/or non-disabled people skilled in enabling self-advocacy
- not be shaped by outside expectations of non-disabled people
- be given space and time to grow and develop
- be built on the strengths of the group members
- be taken seriously by services which should not pretend to support self-advocacy when they really do not
- have their advice and decisions listened to carefully and acted upon by service workers
- have real power and representation in important decisions about services which affect users’ lives
- become a pressure group for positive change in services
- empower group members to change their own lives with the support of other disabled people”³⁵ (pp.144-145)

4.3.2 Effectiveness of self-advocacy

The outcomes and impact of self-advocacy occur both at the individual and more systemic level. Some important legislative and policy changes have been attributed to action by self-advocates (for example the closure of institutions and legal cases on specific issues)³⁶. However, the strongest evidence relates to benefits at the

³⁴ Clare 1990

³⁵ Downer J. and Ferns P. 1998, ‘Self-advocacy by Black People with Learning Difficulties’ in Ward (Ed), *Innovations in Advocacy and Empowerment for People with Intellectual Disabilities*, Lisieux Hall Publications, Lancashire, England, pp.141-150.

³⁶ Bersani H. Jr 1998, ‘From Social Clubs to Social Movement: Landmarks in the development of the international self-advocacy movement’ in Ward (Ed), *Innovations in*

individual level such as gains in confidence, assertiveness and communication skills³⁷. There are a number of studies which identify the effectiveness and benefits of teaching self-advocacy skills to students with intellectual and other disabilities³⁸. Improvements in self-worth and self-esteem have been identified and that the effect of self-advocacy on those without a disability can be a catalyst for change³⁹.

4.3.3 Limitations of self-advocacy

Some cautions have been sounded about self-advocacy; some are general observations while others are based on experience in particular countries. For example, an exclusive focus on self-advocacy is advised against as it can lead to a lack of access to or focus on other types of advocacy which may be beneficial for an individual at specific points in time⁴⁰.

A number of limitations to models of self-advocacy in England included a neglect of concrete issues in favour of arguments about inclusive processes; self advocacy that has become part of the “panoply of government”; funding from sources which impose conditions such as funding contracts, targets and deadlines; and rivalry between self-advocacy organisations leading to difficulties in establishing a national organisation⁴¹.

Issues inherent in the model itself are also raised as concerns; such as vulnerable individuals being placed in situations of increased risk if they are encouraged to challenge powerful interests without adequate support⁴²; and self-advocates being used by the ‘disability system’ to provide their views rather than challenge the philosophy of services and the system⁴³.

Advocacy and Empowerment for People with Intellectual Disabilities, Lisieux Hall Publications, Lancashire, England, pp.59-76.

³⁷ McNally S. 1999, ‘Professionalism and user self-advocacy’ in Malin N. (Ed) *Professionalism, Boundaries & the Workplace*, 1999, Chapter 3, pp.47-64.

³⁸ Test D.W., Fowler C.H., Brewer D.M. and Wood W.M. 2005, ‘A Content and Methodological Review of Self-Advocacy Intervention Studies’, *Exceptional Children*, Vol.72, No.1, pp.101-125.

³⁹ Seymour S. and Peter D. 2004, ‘Disability Advocacy in Australia’ in Goodbody Economic Consultants, *Developing an Advocacy Service for People with Disabilities: International Research Papers*, Vol 2, Feb 2004, Dublin.

⁴⁰ Parsons I. 1994, *Oliver Twist Has Asked For More. The politics and practice of getting justice for people with disabilities*, Villamanta Publishing Service, Geelong.

⁴¹ Buchanan I. & Walmsley J. 2006, ‘Self-advocacy in historical perspective’, *British Journal of Learning Disabilities*, September 2006, Vol. 34 Issue 3, p133-138.

⁴² Cocks E. and Duffy G. 1993, *The Nature and Purposes of Advocacy for People with Disabilities*, Social Research and Development Monograph No.4, Faculty of Health and Human Sciences, Centre for the Development of Human Resources, Edith Cowan University, Perth and Commonwealth Department of Health, Housing, Local Government and Community Services, Canberra.

⁴³ Dowse L. 2001, ‘Contesting Practices, Challenging Codes: self advocacy, disability politics and the social model’, *Disability & Society*, Vol.16, No.1, pp.123-141.

4.3.4 Barriers to self-advocacy

Barriers to self-advocacy have been identified in several studies and are listed here^{44,45,46}. All have been cited in the report on models of advocacy funded under the National Disability Advocacy Programme in Australia⁴⁷.

Barriers at the individual level such as:

1. Lack of experience among self-advocates
2. A lack of leadership skills among some people with disability
3. Maintaining individual motivation, concentration and interest
4. Individual characteristics which may impair the person's ability to understand their rights and advocate on their own behalf

Appropriate training and support can often address these barriers and explains the emphasis in most self-advocacy groups on training and development and skills acquisition.

'Group-level' barriers have also been described such as:

5. Loss of key members
6. Personal conflicts between group members
7. Overbearing advisors or dependence on advisors
8. Transport difficulties resulting in reduced attendance at meetings
9. Lack of funding to support members attending local and national meetings resulting in non-attendance

Systemic barriers such as:

10. Insufficient monetary resources to access and prepare individuals for self-advocacy and to implement the choices expected to arise as a result of self-advocacy
11. Funders seeking to influence/set the self-advocacy agenda
12. Continued lack of support from the community as a whole
13. Lack of public awareness of self-advocacy and self-advocacy groups
14. Antipathy towards self-advocacy (e.g. convincing parents, caregivers and service providers that self-advocacy is worthwhile and non-threatening).

⁴⁴ Pennell RL, 2001, 'Self-determination and self-advocacy: Shifting the power', *Journal of Disability Policy Studies*, Vol 11(4), Spring 2001. pp. 223-227

⁴⁵ Wolfe PS, Ofiesh NS, Boone RB, 1996, 'Self-advocacy preparation of consumers with disabilities: A national perspective of ADA training efforts', *Journal of the Association for Persons with Severe Handicaps*, Vol 21(2), Sum 1996. pp. 81-87.

⁴⁶ Bramley J, Elkins J, 1988, 'Some issues in the development of self-advocacy among persons with intellectual disabilities', *Australia & New Zealand Journal of Developmental Disabilities*, Vol 14(2), 1988, pp. 147-157.

⁴⁷ Department of Families, Housing, community Services and Indigenous Affairs (2009) *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*. Appendices to the Final Report.

4.4 Group advocacy

Group advocacy is a form of self-advocacy, when a group of people, with a common cause, act collectively to reach their shared goal. Like self-advocacy, it is seen as enabling people to have a voice, enhancing personal identity and raising self-esteem. An important benefit of group advocacy is the way in which the group can act as a support system for individual self-advocates.

The Forum report describes the type of support needed “*if group advocacy is to survive*⁴⁸”:

- Accessible premises (a safe place to meet)
- Transport (if required)
- Personal Assistants (if required)
- Group-work skills (training and knowledge of group dynamics)
- Funding
- Training and capacity building strategies for individuals and the group
- Support mechanisms & structures.
- Administrative back-up.
- A facilitator (should the group require it – but the power dynamics should be firmly rooted and owned by the group).

Successful and fully formed group advocacy also requires elements which work to maintain group life such as:

- a) A democratically elected chairperson, secretary and treasurer
- b) Ground-rules and a code of practice to ensure parity of esteem within the group.

Several studies have highlighted the importance of good advice, facilitation and support, particularly in the early years of a self-advocacy group. Support should ideally come from “an independent facilitator who is not employed by health or social services”⁴⁹. Hayden suggests that advisors/facilitators should⁵⁰:

- Identify when external interests may move the self-advocates away from their primary purpose;
- Support self-advocates in learning how to resolve problems and conflicts;
- Assist self-advocates in setting boundaries (such as time commitments) with others.

⁴⁸ Forum of People with Disabilities (2001) *Advocacy: A Rights Issue*

⁴⁹ Whittell B. & Ramcharan P. and members of People First Cardiff and the Vale 1998b, ‘Self Advocacy: Speaking up for ourselves and each other’ in Ward (Ed), *Innovations in Advocacy and Empowerment for People with Intellectual Disabilities*, Lisieux Hall Publications, Lancashire, England, pp.39-58.

⁵⁰ Hayden (1998) cited in Department of Families, Housing, Community Services and Indigenous Affairs (2009) *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*. Appendices to the Final Report.

4.5 Group advocacy or self-advocacy?

There can be “an inherent tension” when self-advocates come together in a group, with some using the group as a mechanism to gain confidence and skills and the group aim of lobbying for change on behalf of the collective⁵¹. Buchanan and Walmsley explain the reasons for this:

“Self-advocacy as a means of individuals gaining confidence requires a process of inducting new members, whereas if they are to be effective campaigning organisations, self-advocacy groups need people with experience and sophisticated skills in debate and management of budgets and people. These do not sit easily together.” (p.134)

However, others see self-advocacy as having two simultaneous aspects; enabling individuals to “contest oppressive practices and structures”⁵² and that “self-advocacy represents the interests of all people with learning disability in a collective endeavour.” (p. 130-131)⁵³.

4.6 Citizen advocacy

The citizen advocate model was developed initially by Wolf Wolfensburger to help ensure that a vulnerable person would be protected if or when there was no family member that could or would do this. O’Brien’s definition captures the essential elements of what a citizen advocate is and does:

“A valued citizen who is unpaid and independent of human services creates a relationship with a person who is at risk of social exclusion and chooses one or several of many ways to understand, respond to and represent that person’s interests as if they were the advocate’s own thus bringing their partner’s gifts and concerns into the circles of ordinary community life.”⁵⁴ (p.3)

Citizen advocacy has been described as a partnership between two people, the client (often referred to in American literature on the topic as ‘the protégé’) and the independent advocate. Hindle also captures an essential element of the quality of the representation; “*Citizen advocacy happens when a valued and competent citizen who is unpaid and independent, with the support of an independent Citizen advocate office, represents the interests of a person with a disability as if those interests were her or his own.*”⁵⁵ (p.29)

⁵¹ Buchanan I. & Walmsley J. 2006, ‘Self-advocacy in historical perspective’, *British Journal of Learning Disabilities*, September 2006, Vol. 34 Issue 3, p133-138.

⁵² Dowse L. 2001, ‘Contesting Practices, Challenging Codes: self advocacy, disability politics and the social model’, *Disability & Society*, Vol.16, No.1, pp.123-141.

⁵³ Ibid. Dowse (2001)

⁵⁴ O’Brien J. 1987, *Learning from Citizen Advocacy Programmes – Including a Revised Short Form of CAPE: Citizen Advocacy Programme Evaluation Standards*.

⁵⁵ Hindle H. 1993, ‘Citizen Advocacy’, *Australian Disability Review*, 1993 (2), pp.29-34.

The citizen advocate role has two aspects; representative and social, although the representative role is seen as more important⁵⁶. Citizen advocates derive power from being a non-professional and not being a relative of the person with a disability⁵⁷.

4.7 Features of citizen advocacy

These definitions indicate specific features of the citizen advocacy model:

- Advocate in an unpaid, freely given relationship
- Independent of service providers and the wider 'disability system'
- As people in valued roles themselves, the citizen advocate works to foster respect for the rights and dignity of those whose interests they are representing
- Primarily works to represent the interests of the client as if they were the advocate's own.

An independent evaluation of the Citizen Advocacy Dublin service noted for example, that the service was dependent on an organisation which was a provider in the disability sector and that an independent organisation was "an essential part of citizen advocacy"⁵⁸.

4.8 Role of citizen advocate

The Citizen Advocacy Organisation of Savannah, Georgia, describes some of the many ways that a citizen advocate can be involved with a client/protégé⁵⁹:

- **Spokesperson** - to vigorously represent a person's best interests and to help them acquire necessary services and supports.
- **Friend** - to begin an ongoing, hopefully life long relationship that may develop into a true friendship over time.
- **Ally** - to stand with a person during good times and bad times.
- **Monitor** - to evaluate and hold human service organisations accountable for their actions.
- **Mentor** - to offer guidance, affirmation, and direction through their presence, personal example, and advice.
- **Opportunity Maker** - to arrange for a person to take advantage of new or better opportunities in our community in work, education, civic involvement, neighborhood involvement, or leisure.
- **Red Tape Cutter** - to help cut through policies and procedures that can sometimes overwhelm.
- **Representative Payee**- to assume responsibility of a person's finances and to help the person with planning a monthly budget and saving for the future.

⁵⁶ Weafer J. 2003, *Jigsaw of Advocacy: A Research Report*, Woods M. (Ed), Comhairle, Dublin.

⁵⁷ Ward J. 1986, 'Citizen Advocacy: Its legal context', *Australia & New Zealand Journal of Developmental Disabilities*, Vol 12(2), Jun 1986. pp. 91-96.

⁵⁸ Dittmeier, H.L. (2010) An Independent Evaluation of Citizen Advocacy Dublin.

⁵⁹ <http://www.savannahcitizenadvocacy.org/advocacy-action/>

- **Adoptive Parent** - to provide a forever family.
- **Legal Guardian** - to assume court-sanctioned responsibility for a person's major personal or financial decisions.
- **Crisis Advocate** - to respond and be present to a protégé immediately on a short term basis until a long term advocate can be recruited, oriented and matched.
- **Advocate Associate** - to offer skills, talents, expertise, and influence to a citizen advocate who is advocating for his or her protégé. Advocate associates are needed in the areas of networking, political savvy, law, journalism, financial planning, housing, employment, medical, and education.

4.9 Effectiveness of citizen advocacy

It is difficult to measure the effectiveness of citizen advocacy because the quality of the relationship is such a central aspect of the advocacy. Benchmarks against which to assess growth in a citizen advocate programme have been suggested as⁶⁰;

- 15 to 18 matches per year for a new programme (12-15 matches in a rural area) in a programme with two full-time staff
- Established programmes could be expected to grow at a rate of 9-12 matches per year up to about 100 matches supported by two full-time staff with the number of new matches slowing as the number of matches needing support increases

Wolfensberger expressed concerns about the effectiveness of citizen advocacy and these were borne out by a number of studies^{61, 62}. The concerns were primarily that;

- There has been avoidance of both minimally and very highly demanding relationships;
- There has been little orientation towards primarily instrumental and formal relationships (i.e. with the emphasis on the representation aspect of the relationship);
- This has resulted in a low emphasis on the recruitment of formal advocates such as legal guardians, trustees etc.;
- Citizen advocate programmes seem to have addressed themselves primarily to less impaired individuals;
- People living with their families are more likely to be assigned an advocate than people in nursing homes and institutions.

⁶⁰ Page-Hanify B. 1992, 'Citizen advocacy: hopelessly idealistic, successful, or poorly implemented?', *Australian Disability Review*, 92, (2), pp.87-99.

⁶¹ Hadlow J. 1996, 'Citizen Advocacy Observed: Tool or Tokenism?', *Journal of Community & Applied Social Psychology*, Vol. 6, pp.403-408.

⁶² Widrick GC, Hasazi JE, Hasazi SB, 1990, 'Citizen advocacy relationships: Advocate, protégé, and relationship characteristics and satisfaction ratings', *Journal of the Association for Persons with Severe Handicaps*, Vol 15(3), Fall 1990. pp. 170-176.

4.10 Limitations of citizen advocacy

Weafer has identified a number of organisational difficulties that are potentially associated with citizen advocacy⁶³:

- Problems in recruiting sufficient numbers of suitable long-term advocates;
- Any interruption in the advocate:protégé relationship can have a traumatic impact on the protégé's wellbeing if not handled properly;
- Making a good match between an advocate and protégé can be challenging;
- Having a diverse range of advocates;
- A coordinator with sufficient time and resources is needed to manage the scheme;
- The tendency for some advocates to adopt a befriending role rather than an advocacy role;
- The lack of acceptance of volunteers by health professionals;
- Concerns over issues of confidentiality;
- Debate over whether advocates should receive expenses.

⁶³ Weafer J. 2003, *Jigsaw of Advocacy: A Research Report*, Woods M. (Ed), Comhairle, Dublin.

5. What has been achieved internationally in self-advocacy

5.1 The experience of self-advocacy in other jurisdictions

An internet search using the terms 'self-advocacy and disability' reveals a myriad of organisations in this space. The majority are small, voluntary, locally based organisations providing a range of supports and activities for a variety of audiences; self-advocacy being one activity among many. There is also a number of small/locally-based organisations that have a more specific focus on self-advocacy for people with disabilities. The list in Appendix 1 is a sample of self-advocacy organisations identified. Other organisations which have a strong advocacy role have grown from 'family and friends' type organisations. A small number of cross-disability self advocacy groups (e.g. the riot <http://www.theriotrocks.org/>) were identified. There are many resources for self-advocacy which are freely and readily available. One example is a booklet produced by the Harvard Law School Project on Disability called *Change Your Life with Human Rights*⁶⁴. This is described as "a self-advocacy book for people with disabilities who want a better life".

In order to inform this study a refined search focused on identifying organisations with the following characteristics;

- Primary focus on self-advocacy and activities to support that
- Mainly involving people with learning/intellectual disabilities
- Run by people with intellectual disabilities (with support) – this is to distinguish such organisations from others which were founded and are mostly run by family members/carers
- 'Large scale' i.e. have a national remit or are recognised as 'leaders' in the field (e.g. commonly referenced in the sites of other organisations or other publications)

The following organisations were identified which most closely fit this description. Although several are not 'national' organisations they have sufficient scale either in membership, activities or profile to provide useful insights for this study:

Self-Advocates Becoming Empowered (SABE) USA

Advocating Change Together (ACT) USA

Self Advocacy Sydney inc. (SAS) Australia

People First (UK)

People First of Canada

People First Europe

⁶⁴ http://www.hpod.org/pdf/Change_Your_Life_With_Human_Rights.pdf

Details of each organisation are in Appendix 2. Common features of these organisations and their activities and achievements are summarised below.

5.2 Features of national self-advocacy organisations

All of the organisations surveyed are run by people with intellectual disabilities for people with intellectual disabilities. They have similar vision or mission statements around the themes of empowerment and making their voice heard with the aim of achieving equality and greater participation.

Activities: All the organisations have a heavy involvement in training, both for their members (for example leadership development) and for others (for example disability awareness). In addition, most organisations are involved in campaigning for causes identified by their members, providing information to members and others and consulting with external bodies and organisations. All the organisations also emphasise the mutual contact and support that was facilitated by being a member and all held annual or biannual meetings/conferences where all members could meet and get together.

Structure: All the organisations are structured along similar lines, with members paying a small fee to join most organisations (e.g. €5-10), a board and a small number of executive officers. All the board members in the organisations are people with intellectual disability, as were the executive officers. Most of the organisations describe some form of 'shared leadership' or mentors, for example co-directors, who support board members and executive officers in their functions.

Funding: It is difficult to source details on funding. Those organisations that supply this detail receive from 40% to 100% public funding. In the UK, the funding from People First organisations comes from local authorities, although recent cuts in funding have led to the closure of some local organisations⁶⁵.

5.3 Other organisations

Two European organisations; the European Disability Forum (EDF) and Inclusion Europe (IE) share some of the features of national self-advocacy organisations although they are different in important respects. Both organisations involve both individuals and family members. The EDF is cross-disability while IE is for people with intellectual disability and their families. Both organisations are funded by the European Commission and have an important role in informing EU institutions on matters relating to people with disabilities and on policy. Both organisations also

⁶⁵ Funding cuts put future of self-advocacy or in doubt
<http://www.disabilitylib.org.uk/component/content/article/1-latest-news/390-funding-cuts-put-future-of-self-advocacy-movement-in-doubt>

have strong campaigning roles although there was little emphasis on training, which is done at the level of national organisations.

TASH, a US national organisation grew from the human rights interest of a group of university-based researchers in the 1970s and is concerned with advocating with and on behalf of people with severe disabilities⁶⁶. The membership includes people with disabilities, family members, researchers and others and the organisation has a strong focus on self-advocacy and academic research.

5.4 Impact of national self-advocacy organisations

These national self-advocacy organisations for people with intellectual disabilities have worked in a variety of ways and across a number of issues to further their aims.

For example, People First of Canada and the Canadian Association for Community Living have come together to form a joint task force on deinstitutionalisation. The Task Force works to raise awareness of institutions and of the conditions for residents of these institutions. The *Institution Watch Newsletter* is written and produced by People First of Canada and the Canadian Association for Community Living Joint Task Force on Deinstitutionalization. This newsletter monitors and reports on the progress made in Canada in terms of closing institutions and ensuring that all persons with intellectual disabilities live in the community.

An example of the key role a national self-advocacy organisation can play in high level consultation is illustrated by the involvement of Self Advocates Becoming Empowered (SABE) in a series of regional self-advocacy summits currently underway in the US. The Commissioner of the Administration on Developmental Disabilities (ADD) in the US has asked the ADD Network to work with Self Advocates Becoming Empowered (SABE), State Developmental Disabilities Services Agencies and other state partners to hold a series of regional self-advocacy summits. The purpose of the summits is four-fold:

1. to assess what is currently happening in the States in self-advocacy – the support structures, activities, accomplishments and challenges;
2. to plan steps that can be taken to strengthen and enhance current efforts at the state level;
3. to develop recommendations for actions at the national level; and
4. to develop policy recommendations that can lead to a stronger, more effective, and long lasting self-advocacy movement across the country.

All the organisations produce resources and information that has had an impact in raising awareness of the issues for people with intellectual disabilities, leading to

⁶⁶ <http://tash.org/>

improved consultation with and involvement of people with intellectual disabilities in areas ranging from local service planning to national policy discussions.

6. Findings from the consultation

A number of individuals were consulted on this proposed initiative to establish the thinking across various stakeholders as to the features of such an initiative and how best it might be developed. Consultees included senior personnel in organisations within the disability and mental health sectors, Government, semi-state organisations and organisations who engage in advocacy and other activities, including self-advocacy. A list of those consulted is in Appendix 3 and the framework for consultation is in Appendix 4.

6.1 NIDAI as a worthwhile initiative

All those consulted thought that NIDAI was an initiative worth pursuing and developing. It was recognised by most that supporting people to have a voice, with help in articulating their needs if necessary; to be really listened to and have their views taken into account was one of the critical needs of this group in terms of securing their rights and living self-determined lives. There was also a view that people with intellectual disability need to have control over their lives within a civil rights and citizenship context. The importance of changing the attitudes of wider society was mentioned, particularly in terms of the need for people with intellectual disability to be viewed more positively, as full citizens with rights. In the words of one of those consulted; “It’s about being valued as a citizen”.

6.2 How to best support people

In terms of how best to support people to achieve their rights and overcome individual capacity deficits, the most frequent response was to really listen to the person. This type of ‘listening’ involves building a relationship and taking time to really observe what is going on for the person. While this process takes time it was recommended as the way in which the person’s wishes are revealed and become clear. Supporting the development of unpaid relationships was also mentioned as a way in which the rights of the person can be protected. It is also necessary to provide training in the ‘technical skills’ of advocacy, such as listening, debating, public speaking etc. In practical terms, the enactment of the Mental Capacity Bill was mentioned by several consultees as an important and necessary step forward in this area.

6.3 Role of citizen advocacy

Citizen advocacy as a model for supporting people with little verbal communication was suggested to consultees. There was general support for this model as a way of ensuring the voice of these individuals was heard. Other methods suggested included creative ways of communicating such as art and drama.

Some consultees observed that this model may have a niche role – i.e. only for some people with intellectual disability and only for a small number of citizen advocates as a long-term relationship may not be realistic for many people who cannot provide that level of commitment. It was noted that very good training and

supervision are required to ensure the citizen advocate stays true to representing the person and not 'what they think the person wants'. It needs to be "based on a genuine respect for rights". The friendship part of this relationship is also very important as this can be crucially missing from people's lives. There are lessons that can be usefully learned from the experience of advocating for children both in terms of exercising appropriate protections against exploitation and avoiding paternalism in that context.

6.4 Suggested features of the NIDAI

The need for a strong structure that supports the objectives of the initiative and facilitates growth and development was emphasised. A possible structure for the NIDAI was described, which included local groups which are supported by regional/provincial groups, a board and a chairperson (service user), with possibly a co-chair. It was widely agreed that the initiative should be an independent, self-advocate-led organisation, although the inclusion of a strong steering committee in the early years was recommended. This steering committee should have a mix of people with and without intellectual disability, be self-advocate-led with a range of people with different skills but no vested interests. Several consultees recommended a model of shadowing/mentoring or co-positions for the key executive positions and the chair of the board, at least in the early years. Other features of the initiative as described by consultees included:

- A funding source that maintains independence;
- A group of committed individuals with a strong vision and clear objectives – this helps in communicating with families and service providers as to what the initiative is about;
- The initiative needs to set its own agenda and be established in a way that promotes real involvement and respect so as to avoid tokenism – others have to engage with the NIDAI on the person's terms;
- The initiative would undertake advocacy of an appropriate adult nature, have a role in highlighting national/important issues, act as a network and resource and provide training and skills.

There was some coherence on features that the initiative should not have or avenues it should not pursue. In particular it was felt by several consultees that the initiative should not be led or located within a service provider or the HSE. Other recommendations were that the NIDAI should not:

- Make assumptions about the capacities of individuals;
- Rush things – the pace will be different;
- Get bogged down in micro concerns that could be better handled at local level – this is about national 'big' issues;
- Have a strong association with volunteering and charity. This initiative should be about adding value to people's lives and respecting their citizenship.

There were also recommendations about features or ways of working that the NIDAI should have:

- Have people with intellectual disability involved in every aspect;
- Avoid tokenism in every way – plan so that this is avoided and so that the initiative sets the agenda;
- Learn from others who have done this and be prepared to start again if the first approach is not successful;
- Always look for the mainstream option;
- Have good staff with the right attitudes;
- Consolidate before taking the next step – take it slowly and allow time for learning and assimilation of ideas;
- Carry out a mapping exercise. There are many small initiatives that can be pulled together and coordinated to great effect;
- Have some focus on social activities; this is an important aspect of getting people together;
- Get leaders together to drive this;
- Have a strong high value brand and identity;
- Develop a model that can be replicated in/have relevance to, local communities;
- Make sure people have enough training to have the skills to do what they are asked to do;
- Go beyond the usual suspects – involve the ‘seldom heard’ – not just about the most articulate;
- Avoid putting words in people’s mouths; everything should be in their own words;
- “Start small and stay small until it’s ready to fly”;
- Provide positive and constructive support for the self-advocates.

6.5 Location for the NIDAI

There were mixed views on where best the NIDAI might be located to start up. There were several recommendations that the initiative be attached to a non-disability, ‘neutral’, ‘mainstream’ organisation, possibly one that has a human rights remit. It was posited that the initiative could be hosted for a number of years and then become more independent. There were suggestions that an organisation like Inclusion Ireland could also be a suitable host. However reservations were expressed by some on the basis that Inclusion Ireland is strongly identified with parents of people with intellectual disabilities. On the other hand, it could be argued that Inclusion Ireland’s strength is that it is inclusive of all interests concerning intellectual disability in Ireland. But this might suggest that hosting an organisation like NIDAI – which would be fundamentally partisan – might not sit easily, in practice, with Inclusion Ireland’s concern to maintain relationships with all relevant stakeholding interests. The advantages of a ‘host organisation’ were that

organisational policies and procedures would be in place that could be easily adopted (with adaptation if necessary). An existing organisation would already have links to useful external organisations both nationally and internationally. There was a sense that beginning with a host organisation would help ensure longevity and strategic development. One possible disadvantage is that the host organisation may be tempted to intervene to sort out issues or challenges.

7. Features of a national self-advocacy organisation

7.1 Features to Shape the Initiative's Design

Combining our learning from the literature review, the desk research on self-advocacy models in other jurisdictions, and the consultative soundings undertaken as part of this project, it is possible to identify several features that seem to be important in designing a national self-advocacy initiative for people with intellectual disabilities in Ireland. These include:

- That the orientation of the initiative would come from a civil/human rights – rather than a disability – perspective;
- That it would also adopt a strengths-based and presumption of capacity approach;
- That it would be independent of service providers and funders (including government);
- That funding would ideally be via an independent intermediary or, at least, at arms-length;
- That it would be led, and key decisions determined, by people with intellectual disabilities;
- That it would be empowering of its members and activists;
- That, in acknowledgement of the constraints of intellectual disabilities, it would be supported by allies who do not have an intellectual disability but who are committed and sympathetic to the principle of self-determination;
- That it would adopt an organisational model that is clear, appropriate, responsive and accountable – and that it is capable of change/adaptation in the light of experience;
- That it be realistic in terms of timeframe – that it would adopt a long-term developmental perspective and a pace of development that reflects this (it is also critical that funders appreciate the importance of this);
- That the inherent tension between the commitment to ensure that the initiative is led by people with intellectual disabilities and the reality that it needs to be pioneered and funded – at least in its earliest stages – by other stakeholders is acknowledged and, as far as possible, reconciled.

These, then, are some of the key elements that have informed our consideration of an appropriate design for a national intellectual disability advocacy initiative. They also imply a number of other important elements (e.g. innovation, leadership, governing arrangements and operating models) that need to be made explicit in mapping out how such an initiative might become a reality – and these will be addressed in the following paragraphs.

7.2 Catalysing the Initiative

A critical issue is where the genesis of such an initiative might come from. It will not be formed by a bolt from the blue, nor is it likely that it will develop solely from the spontaneous actions of one or more people with intellectual disabilities. It is more likely that it will need to be initiated by independent actors with the support of funders – but how can this be reconciled with the aspiration of a user-led initiative?

Pragmatically, it seems that the most realistic model is that a combination of activists and funders would intentionally establish an embryonic advocacy movement for people with intellectual disabilities with the aspiration that it would become a self-advocacy movement within a specified period, e.g. 3 to 5 years. This would need to be accompanied by a set of specific targets and performance indicators within this timeframe – most particularly that the initiative had succeeded in achieving the endorsement, engagement, and active participation of a significant (and defined) cohort of people with intellectual disability within the specified period.

7.3 Achieving the Endorsement of People with Intellectual Disabilities

The NIDAI can only succeed if it attains the authority and credibility that comes with its ownership by significant numbers of people with intellectual disabilities and their endorsement of its goals and priorities. Achieving this will clearly involve a well-considered process of reaching out at both the individual and group levels, with the support of parents and siblings and service providers. This is likely to be gradual – based on progressive results – as it is not realistic to expect unquestioning buy-in. It will also require the setting and measurement of modest targets, as it will be important not to over-reach or over-promise. Nevertheless, it should be possible to demonstrate both significant progress and positive trends by years 2 – 3. At this point, also, the transition of ownership and control of the initiative from activists to users should have begun though it may, realistically, take up to five years to complete.

An alternative approach would be to establish the initiative from the outset on the model that is envisaged for the long term. This would likely involve the establishment of governance and operational structures controlled by people with intellectual disabilities – albeit with the support of activists – from the outset. We have considered this option but have concluded that it has two major drawbacks: 1) the challenge of getting the initiative off the ground while the leadership is on a steep learning curve would probably prove too great, while 2) it would involve the leadership being selected by the activist-initiators, whereas we believe that it would be preferable to allow the leadership by people with intellectual disabilities to emerge more organically.

7.4 Governance Arrangements

The initiative will potentially bring significant governance challenges. As already indicated, we believe it to be important that the initiative be under the control of a Board comprising up to 10 people with intellectual disabilities, with the assistance of independent “allies” whose sole role is to support them in achieving their goals. Our view is that this will take some time to accomplish but that the transition should take place as soon as possible but take as long as necessary – in other words, it should be neither prolonged nor rushed. It is impossible to state categorically what the most appropriate timeframe might be but our best estimate is that it might begin by Year 3 and be well-advanced by Year 5. Members of the Board would be appointed or elected for a defined term and provision made for staggered rotation and succession. Careful consideration needs to be given to the role of allies – and to their selection and appointment. It is important that they would offer appropriate advice, support and assistance, but not be over-bearing or controlling. They will be very special people with a mix of highly developed skills and personal qualities.

7.5 Operating Model

The initiative will employ staff to execute its strategic priorities, under the direction of the Board. The growth of the staff complement will reflect the development of the initiative and will be commensurate with the growth of its operations and membership. We envisage that NIDAI will provide support at the individual level while also seeking to influence policy and practice through group advocacy. One operational question for further consideration is whether citizen advocacy might co-exist with self-advocacy within NIDAI. As we have seen (Section 4.6), citizen advocacy has certain attributes – and shortcomings – but may have a role, particularly in the case of people with intellectual disabilities who have difficulties in articulating their needs. However the experience in some areas, that citizen advocate programmes seem to have addressed themselves primarily to less impaired individuals, needs to be addressed if a citizen advocate programme is to successfully meet the needs of those who cannot articulate their needs. Similarly, the interface between individual and group advocacy on the one hand, and the appointment of legal guardians and trustees on the other, warrants further exploration.

7.6 Stand-alone Initiative or Part of an Existing Organisation?

We received mixed views on this subject from those we consulted, although a significant number acknowledged the challenge of establishing a new organisation. It was observed by some that a new organisation was more likely to be seen as neutral, unencumbered by associations (whether positive or negative) with existing organisations – or vested interests. In similar vein, one respondent felt that being associated with an existing organisation might constrain NIDAI, as its interests could conceivably be in conflict with those of the parent organisation.

We find these to be important considerations but have reservations about immediately creating a new stand-alone organisation – both because of the substantial challenge and uncertain nature of this particular pioneering initiative, and of the risk of dissipating energy and focus on start-up organisational matters. Therefore we find the suggestion that NIDAI be temporarily hosted by an existing organisation – but have significant scope to function independently within this arrangement – to be quite compelling. In effect, we strongly believe that there is virtue in seeking an arrangement where the host organisation provides accommodation and administrative support (including accounting and payroll, human resources, etc.) thus enabling NIDAI to focus on advancing its strategic development under the direction a Board/Steering Committee. One advantage of such an arrangement would be that the host organisation would already have well developed administrative and financial policies, procedures and expertise which would allow NIDAI to concentrate on building membership and advancing its strategic priorities. As NIDAI develops, over a reasonable and agreed period, it would eventually withdraw from this hosting arrangement to become fully independent. Obviously the detail of such an arrangement would need to be carefully negotiated and would presumably involve a reasonable payment to the host organisation, but the arrangement offers potential benefits to both parties. Similar arrangements have worked satisfactorily in other comparable circumstances (for example, the then Irish Association of Young People in Care being hosted by Barnardos for a number of years) and could be drawn upon in ensuring that this particular hosting arrangement operated satisfactorily.

We discussed a hosting arrangement for NIDAI's early years with several of our consultees and received a broadly positive response to the concept. Of interest was the suggestion that NIDAI should not be hosted by either a statutory or voluntary disability service provider – because of concerns that its independence might be compromised, and to avoid potential conflicts of interest. Furthermore, it was strongly suggested by a few respondents that a hosting arrangement should be sought, not with an organisation within the disability arena – which, it was claimed, would be limiting and would reinforce the “pigeon-holing” of people with intellectual disabilities – but with a mainstream organisation that is focused on issues of human rights, citizen participation and equality.

We find this an insightful perspective that is consistent with the values and principles that underpin the concept of self-advocacy for people with intellectual disability. Rather than starting from a deficit perspective, it emphasises their status as citizens first, presumes capacity, promotes their participation in mainstream society and would have supportive resources and expertise to offer, particularly in NIDAI's formative years. We consider, therefore, that this would be the preferred hosting arrangement and – although we have not explored its feasibility – we believe that an association with the Irish Human Rights Commission for NIDAI's first five years (at least) to be an attractive option. The IHRC would lend authority and credibility to

NIDAI – as well as a range of administrative supports – as it sought to establish itself in its early years. Should the IHRC be unable to offer its support as a host organisation, another option would be to explore the possibility of the Citizen’s Information Board performing this role. As we have noted (see page 7) the CIB has already established a new National Advocacy Service to provide independent, representative advocacy services for people with disabilities, so it has relevant insights and expertise in a related area. Again, it would lend authority and profile – in addition to valuable organisational supports – to NIDAI should a hosting arrangement be negotiated and it seems that it would be permitted by CIB’s statutory function to “To support the provision of, or directly provide, advocacy services for people with a disability”.

To summarise, we consider that it would be prudent for NIDAI, in its early years, to seek a hosting arrangement with an established organisation to provide administrative and other organisational supports while it is focusing on establishing its mission, membership and profile. We think there is a compelling argument to seek such alignment with an organisation that is in the mainstream and that is focused on issues of human rights, citizen participation and equality – rather than one that is exclusively identified with disability. We have identified a hosting arrangement with the Irish Human Rights Commission as the ideal, but consider the Citizens Information Board as an attractive alternative.

7.7 Funding and Sustainability

It appears that to establish NIDAI at a significant level of operation will require initial investment from either Government or philanthropy or, preferably, both. However both the literature and our consultees have identified the risks of “capture” – i.e. the constraints on the initiative’s independence of an overly close or dependent funding relationship, or the appearance of such. One way to address this, at least in terms of the optics, would be to create an arms length relationship between NIDAI and its funders by routing the funds via an intermediary or fiscal agent, such as Genio – although this is not the only fiscal agent option.

In any event, from the outset it will be important to ensure that NIDAI has the prospect of sustainability beyond the term of any initial funding. Also, it would be desirable to access funding from diverse sources in order to limit dependency on any single funding source while spreading the risk of any one source running dry. We believe that NIDAI has potential to attract funding from a number of different sources, although it may take some years before all of them will reach their potential. In the short term, therefore, we think there will be an inevitable reliance on funding from government and philanthropic sources. Funding from these sources might continue into the future, but the development of other sources would serve to reduce their significance proportionally and it would be advisable to develop other sources as soon as practicable. These additional funding sources could include:

- a) **Membership fees** – a key measure of NIDAI’s relevance will be the degree to which it becomes accepted and endorsed by people with intellectual disabilities as the organisation (or movement) by which they perceive their rights can be gained and vindicated. Building a significant membership will be important strategically, but levying a modest membership fee (e.g. €10 per annum) will make a significant contribution to the initiative’s success, both financially and symbolically.
- b) **Earned income** – as the initiative grows and becomes established, it will have potential to trade its knowledge and expertise commercially, for example, through the provision of training and consultancy to state agencies, local authorities, service providers, etc. If built into the design of the initiative, the development of this capacity could generate significant recurring income.
- c) **Contributions from service providers** – if considered appropriate, contributions towards the establishment of seed capital could be sought from the many service providers throughout the country. There might be potential for continuing funding from service providers but care would need to be taken to ensure that this would not compromise the initiative in any way.
- d) **Establishment of a Designated Foundation** – the establishment of a designated fund may offer significant continuing income to NIDAI. Investments could be made in the fund over time by any number of donors with the specified purpose of supporting NIDAI’s activities and goals. Donations from service providers could be directed to this fund, as might donations from corporates. In particular, families of people with intellectual disabilities may also see it as an attractive vehicle for their donations, including legacies. In this way parents, especially, would have the assurance that they were contributing to the strengthening and sustainability of this self-advocacy initiative. In most instances donations would be tax-deductible. A specific strategy would be required to differentiate the fund from other funds and to develop and communicate the proposition to potential donors. The foundation would be managed by appointed trustees although there would also be the option of its being managed by the Community Foundation of Ireland (<http://www.communityfoundation.ie/>).

Although it was not within our terms of reference to undertake feasibility studies on the potential of each of these sources of funding, we are confident that each has a contribution to make – in addition to the potential of continuing public and philanthropic support – towards securing the sustainability of NIDAI into the medium term, with strong indications that it could be sustainable in the long term once it had demonstrated achievement and its credentials in terms of the central and controlling role of people with intellectual disabilities themselves.

7.8 Vision for NIDAI

Drawing these disparate considerations together, we now offer a vision of how the successful development of NIDAI might look in the future – specifically taking a 2014 and a 2021 perspective.

By 2014, NIDAI is an embryonic and innovative initiative that has been established by an alliance of people with intellectual disabilities, activists and funders to strengthen the voice of people with intellectual disabilities and to significantly increase the recognition and vindication of their rights. Following an extensive period of consultation with people with intellectual disabilities, using a variety of techniques (not exclusively verbal) – and with other stake-holding interests (families/carers, service providers, policymakers and funders), a consensus has emerged on the establishment of the initiative and an operating model for the first three years has been agreed. This has led to the formal establishment of the initiative with the active participation of people with intellectual disability. While a group of volunteer “allies” has advised and actively participated in the initiative’s establishment, people with intellectual disability have shadowed them at each stage and it is envisaged that within two years the roles of the two groups will reverse, with the leadership emerging from people with intellectual disability who have been involved in the start-up phase. Thereafter the volunteer allies will support and advise in the development of the initiative but decision-making will be the preserve of those with an intellectual disability. This will require the painstaking development of processes and techniques to ensure that the intent that people with intellectual disability lead the initiative is respected and implemented.

The establishment of the initiative is funded through a combination of Government and philanthropic funds, channelled through Genio as an independent and honest broker to facilitate the consultative and start-up phases. As people with intellectual disabilities assume control of the organisation, a membership drive – which will include the collection of a modest membership fee (in the region of €10 per year) – will be undertaken. Steps are also afoot to establish a specific community foundation to receive and administer funding to support the initiative. It is envisaged that the foundation will be a vehicle for siblings and families – as well as other stakeholders – to contribute financially in achieving NIDAI’s goals and sustainability. In time, it is expected that NIDAI will also develop an income-earning capacity through, for example, the provision of training and consultancy, which will also support its sustainability.

By 2021, NIDAI is a well-established advocacy organisation/movement that has made great strides in giving voice to the needs and interests of people with intellectual disabilities – both individually, and as a coalition of shared interests – thereby raising awareness of, and securing, their rights. It is an authoritative voice that commands the allegiance of people with intellectual disabilities throughout the Republic of Ireland – and of their families/carers – and is recognised by service

providers, statutory agencies and Government. Having established its authority, and operating both assertively and constructively, NIDAI is routinely consulted by government and public agencies on policy matters and by other stakeholders including service providers, media, etc.

NIDAI operates with people with intellectual disabilities at its core, giving leadership through their participation at all levels of the initiative and determining its key decisions and activities, with the support of volunteer allies – who assist in the governance of the initiative – and key staff. Through continual learning and the accumulated experience and wisdom gained over ten years, NIDAI has refined and developed its operating model and is now recognised as a sophisticated and pioneering movement of people with intellectual disabilities both nationally and internationally. It is funded through a combination of membership fees, arms-length government and philanthropic support (via an intermediary organisation), earned income (from consultancy and training) and through grants from a community foundation specifically established for this purpose.

8. Making NIDAI a Reality

8.1 First Steps

Should Genio, following review and reflection on this report, decide to accept its findings, a number of steps will be required to begin the process of implementation:

- Appoint a Steering Group with specific terms of reference to establish the initiative;
- Provide, or source, resources (see indicative early costs below) to support the implementation process;
- Negotiate with the prospective host organisation to agree a formal contract or Memorandum of Understanding;
- Appoint a Project Manager, with administrative support, to lead the operational aspects of implementation;
- Begin a strategic planning process for the first five years.⁶⁷ The planning process should include a series of consultative meetings with people with intellectual disabilities around the country and existing self-advocacy groups. In addition to seeking inputs to the planning process, these sessions would also seek to
 - Raise awareness of the initiative and its goals;
 - Gain buy-in and support for the initiative;
 - Identify people with intellectual disabilities who may be motivated to become actively involved with the initiative;
- Add people with intellectual disabilities to the Steering Group as early as possible.

8.2 Indicative Budget

The main items of expenditure in the initiative's early years will be the costs of the Project Manager and administrative support, the costs of the hosting arrangement (which will include back-office support costs including payroll), and the cost of developing the strategic plan – which will include costs associated with the regional consultative meetings, travel and subsistence, etc.

Notwithstanding the difficulty of quantifying an appropriate budget for an undertaking of this nature, we believe that it should be possible to fund the initiative with a budget of €500,000 for the first three years. Thereafter it is likely that costs will rise as other staff are added, leading to increased activity levels, and as communications and other externally focused functions are developed.

⁶⁷ A three-year strategic planning timeframe would be more conventional – however, because of the nature of this particular initiative and on the advice of consultees, we believe it would be more appropriate, in this instance, that the first plan cover a five-year period.

9. Concluding Observations

The genesis of this proposed initiative lies in the conviction that people with intellectual disabilities share with their fellow citizens a fundamental need for self-actualisation and participation in society – but that many are denied these opportunities due to a combination of barriers that they typically encounter. Although there are a number of important self-advocacy and citizen-advocacy initiatives that currently exist and provide much-needed support, they have generally not reached scale and many are under-resourced and/or face considerable sustainability challenges.

While the need for people with intellectual disabilities to exercise control over their lives within the constraints of their disability is long-standing, there are at least now some promising features in the environment that offer potential and hope for the success of a new self-advocacy initiative. These include important policy and legislative shifts that emphasise capacity and person-centredness; increased focus on participation and rights – supported by international instruments; the opportunity to learn from self-advocacy initiatives in other spheres including mental health, and physical and sensory disability; significant developments in self-advocacy for people with intellectual disabilities internationally, and accessibility to the experiences and insights of these activists, allies and academics; and the existence of intermediary organisations and funders with the necessary conviction and capacity to achieve real impact.

The exploratory work that has underpinned this scoping study has included a literature review, desk research, consultative meetings and deliberations. It has established that there is widespread support for a self-advocacy initiative and contributed relevant and insightful advice. In evaluating all of the inputs, it has become clear that a self-advocacy initiative should be imbued with a civil and human rights perspective – out of a realisation that this is, fundamentally, what this enterprise is all about. People with intellectual disabilities are people, and citizens, first. They have capacities as well as capacity deficits, as we all have. While we acknowledge the real constraints of an intellectual disability we assert that it needs to be understood in the context of its specific impact on the individual, not aggregated or generalised.

This perspective implies a series of values and principles that we have tried to reflect in NIDAI's key features, which are outlined in section 7.1. We have also tried to be pragmatic – we recognise that an initiative needs to be catalysed, and that this will require the leadership of activists and funders from the beginning. But it must not only be accommodating of people with intellectual disabilities from the earliest stage – its initiators must be prepared to hand over control as early as it is feasible to do so, yet remain as allies in a supportive and facilitative capacity. We think that the

initiative will need to be nurtured, and that funders and other stakeholders will need to be patient, if it is to be given the time and opportunity to succeed. It is more likely to gain traction if it can reach out and gain the interest and endorsement of people with intellectual disabilities at an early stage – this can be facilitated by a hosting arrangement which obviates the need to focus energies on statutory organisational issues from the outset.

Importantly, NIDAI has the potential to be sustainable through a combination of funding from diverse sources. It will, however, be important that attention is given to developing each of these sources at an early stage.

NIDAI is a timely and potentially transformative initiative. It will meet many challenges but, if overcome, it can become an authoritative and influential voice for people with intellectual disabilities in Ireland. Ultimately, its success will be determined by the extent to which people with intellectual disabilities own it, and look to it for support in expressing their citizenship through participation in society and making choices and decisions every day.

Appendix 1

A sample of locally-based self-advocacy organisations

[Advocates in Action—Rhode Island](#)

Rhode Island's Statewide Self-Advocacy Organization.

[Central England People First](#)

Run by and for people with learning difficulties to improve the lives of all people with learning difficulties.

[People First of Anchorage, Alaska](#)

To promote self-advocacy by and among people with disabilities, ensuring that such people are treated as the equals of other citizens; that they are given the same rights, responsibilities, choices, decisions, and chances to make mistakes like everyone else.

[People First of California](#)

PFCA serves as a role model for people with developmental disabilities in personal empowerment, leadership, and advocacy. PFCA is also a resource to professionals in the developmental disabilities service system and provides the general community with education on subjects useful and beneficial to people with developmental disabilities.

[People First of Connecticut](#)

People First of Connecticut is a statewide self advocacy organization that meets every other month in a central CT location. Members from 16 chapters come together to share self advocacy news and issues.

[People First of Illinois](#)

People First of Illinois is committed to empowering people with disabilities to make their own decisions and choices and to speak for themselves. We will continue to advocate to improve the lives of people with disabilities in our state, and will work to ensure that persons with disabilities are treated equally and are active members of their community.

[People First of Missouri](#)

People First of Missouri is a statewide organization formed by, run by and which exists for persons with developmental disabilities. Currently there are 40 chapters across the state of Missouri with approximately 850 members.

[People First of New Hampshire](#)

A non-profit organization directed by people who have disabilities for the purpose of self-advocacy.

[People First of Oregon](#)

People First is a self-advocacy organization of developmentally disabled people who have joined together to learn how to speak for themselves.

[People First Wisconsin](#)

A statewide self-advocacy organization for people with disabilities. We are dedicated to enabling people with disabilities to have our voices heard.

[People First of Wyoming](#)

People First - Disabilities Second. People First of Wyoming is for people with disabilities (Self-Advocates) learning that they have a voice to speak up in how they want to live their lives

People First of Germany <http://www.people1.de/>

People First Vienna <http://www.viennapeoplefirst-gaw.at/>

People First Japan <http://www.pf-japan.jp/>

[Speaking For Ourselves—Pennsylvania](#)

Speaking For Ourselves is a group of people with disabilities in Pennsylvania, USA. Their web page tells about their philosophy of self-determination; gives a statement on closing institutions; has tips about using computers and the web for people with disabilities; shares songs about transportation, institutions, and other topics; and has links to other disability web pages.

[Self-Advocacy Association of New York State](#)

The Self-Advocacy Association of NYS is an organization for and led by people with the challenge of a disability to assure the civil rights and responsibilities that include the opportunities and choices of equal citizenship.

Some of the organisations on this list are taken from the profile of Regional/State Resources provided on <http://www.familyvillage.wisc.edu/general/selfd.html> .

Appendix 2

Self-Advocates Becoming Empowered (SABE)

<http://www.sabeusa.org/>

Self Advocates Becoming Empowered (SABE) is the national self-advocacy organization of the United States. Founded in 1990, the organisation works for the full inclusion of people with developmental disabilities in the community throughout the 50 states and the world⁶⁸.

Mission statement: To ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends; and to learn from their mistakes.

Current goals:

- Eliminate institutions;
- SABE will support affordable and accessible housing for all people in the community;
- National healthcare for all people;
- Equal employment opportunities for equal pay for all people;
- People with disabilities will have self-advocacy at all stages of their lives with funding to support state, local and national self-advocacy organizations;
- SABE will educate people with and without disabilities on the options, choices and alternatives to guardianship so that full guardianship is not an option whenever possible;
- Relationships;
- SABE will be a political powerhouse to work on legislation that effects people with disabilities lives;
- SABE will advocate for individualized services for all people with disabilities;
- SABE will support flexible and available accessible transportation (airlines, trains, buses) for all people in the community across the nation; and,
- SABE will educate people – all people - about disability issues that are important in their lives.

Structure

The USA is divided into 9 regions, each with a representative. There is an Executive committee of 5 people and a board with 12 members. No information could be obtained on the funding of the organisation.

⁶⁸ <http://www.sabeusa.org/>

Advocating Change Together (ACT)

Advocating Change Together (ACT)⁶⁹ is a non-profit US-based grass-roots disability rights organisation run by and for people with developmental and other disabilities in Minnesota. ACT's mission is "to help people across disabilities see themselves as part of a larger disability rights movement and make connections to other civil and human rights struggles". ACT's programs build self-advocacy in three ways: **personal empowerment, disability awareness, systems change**. ACT is made up of general members (approximately 100), a board and a staff. The organisation is self-advocate-led with ally support.

Structure

ACT is "a place where members can become leaders". Through events and gatherings, members get to know each other and build a sense of community. Membership is open to anyone (\$10 for membership) and members alone decide who is on the board. The organisation is managed by a board of 16 people—all individuals with disabilities. Board members take part in leading ACT programs. They decide what ACT's policies will be and approve new programs. The board is considered to be one of ACT's strongest assets; "This is a board where you're supported to build your skills and become a leader".

The organisation is run day-to-day by six staff. ACT believe that "shared leadership is key to self-advocacy". ACT has two co-directors, one of whom is a person with a disability. The administrative director is a parent of a child with disabilities. The remainder of the staff consist of an organiser, an office assistant and an additional office worker who has a developmental disability. Other people are hired on short-term contracts for specific tasks such as designing new programs, print materials, and writing grant proposals.

Funding

Budget is about \$500,000 per annum which comes from a mix of public, philanthropic and earned income. Their goal is to have about one third of each⁷⁰.

Programmes

ACT runs many training programmes. On their website eight disability awareness workshops exploring different aspects of Disability Act 2005 (US) were described, 14 systems change workshops on leadership development, community development self-advocacy etc. and 7 Personal Empowerment workshops.

⁶⁹ <http://www.selfadvocacy.org/index.htm>

⁷⁰ Personal correspondence

Self Advocacy Sydney Inc Australia

<http://www.sasinc.com.au/>

Self Advocacy Sydney Inc is an organisation run by and for people with intellectual disability whose vision is that people with an intellectual disability will be valued members of the community, have their voices heard and rights supported. The organisation serves the Sydney Metropolitan Area only.

SAS works by:

- Giving training support and information to all members / consumers to develop their skills as self advocates;
- Providing information and education to the community about self advocacy and the rights of the people who have Intellectual Disability;
- Developing strong links with other advocacy and community groups.

Organisation : SAS is run by an Executive Board which consists of four Office Bearers - President, Vice President, Treasurer and Vice Treasurer, and three other Board Members. This Executive Board makes decisions with help from support people of their choice. All Executive Board members are selected for a 2-year term at every second Annual General Meeting

Funding: This service is funded by the Australian Government through the Department of Families, Housing, Community Services and Indigenous Affairs. Costs were \$184,000 Aus in 2008/09.

People First England

<http://www.peoplefirstltd.com/>

People First is an organisation run by and for people with learning difficulties to “raise awareness of and campaign for the rights of people with learning difficulties and to support self advocacy groups across the country”.

Structure: People First have members from all over the UK with over 150 groups and organisations. The organisation is run by a management committee with seven members most of whom have learning difficulties. People First are involved in several activities including:

- providing an ‘Easy Ready’ service which makes reports, forms and publications accessible to disabled people with learning difficulties
- training for professionals and groups who work with disabled people with learning difficulties and want to improve their communication skills and work practices
- training for groups on self advocacy, sexuality, disability equality and more
- consultancy for self-advocacy groups who want to develop as an organisation and become user-led
- conferences about campaigning and good practice in self advocacy groups
- providing publications in accessible format on a range of topics from disability equality to becoming a charity.

People First of Canada

http://www.peoplefirstofcanada.ca/visions_goals_en.php

People First of Canada is directed and controlled by people who have intellectual disabilities. The organisation was formed because “some of the people in our communities felt that they were not considered as people first. They felt that they were talked about, talked to, thought about, and treated according to the disabilities that others labelled them with. Over the years people have been called *mentally handicapped, developmentally disabled, cognitively challenged, intellectually disabled*, and many other labels. In order to avoid hurting peoples' feelings and to avoid using labels when we talk about the many different members of People First, we will use the term *people who have been labelled*.”⁷¹

The Board of Directors consists of five people with disabilities, and there are a further 14 board members from different states/provinces of Canada. The organisation works to

- Support people who have been labelled to speak for themselves and to help each other, and
- Ensure that what people who have been labelled have to say is heard.

This organisation has a stronger emphasis on advocating on national issues and campaigning and less of an emphasis on training compared to ACT and SAS for example.

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People First Europe

<http://www.europepeoplefirst.org/>

People First Europe was established as a self advocate network at the European People First conference in Göteborg, Sweden February 2007⁷². This organisation is for self-advocacy organisations which are independent from parent's organisations and service organisations. Member organisations are owned and controlled by self-advocates and only people with an intellectual disability are allowed as voting members of People First Europe.

The overall issue for the group is "Smash the institutions". Different member organisations have responsibility for different matters. For example, People First Scotland has responsibility to look for funding for the activities of the European organisation.

People First Europe seems to be in a developmental stage.

⁷² <http://europepeoplefirst.org/>

TASH Equity, Opportunity and Inclusion for People with Disabilities

<http://tash.org/>

The mission of TASH is “to promote the full inclusion and participation of children and adults with significant disabilities in every aspect of their community, and to eliminate the social injustices that diminish human rights. These things are accomplished through collaboration among self-advocates, families, professionals, policy-makers, advocates and many others who seek to promote equity, opportunity and inclusion”. TASH works in the following ways:

- Advocacy for equity, opportunities, social justice and human rights
- Education of the public, government officials, community leaders and service providers
- Research that translates excellence to practice
- Individualized, quality supports in place of congregate and segregated settings and services
- Legislation, litigation and public policy consistent with the mission and vision of TASH

The organisation began in the 1970s when a number of university-based researchers came together with a focus on supporting those people with significant disabilities and support needs who are most at risk for being excluded from society; perceived by traditional service systems as most challenging; most likely to have their rights abridged; most likely to be at risk for living, working, playing and learning in segregated environments; least likely to have the tools and opportunities necessary to advocate on their behalf; and are most likely to need ongoing, individualized supports to participate in inclusive communities and enjoy a quality of life similar to that available to all people. The organisation has grown to have a much stronger focus on self-advocacy, with many self-advocates as active members. This focus runs alongside the research focus of many other members.

In 2010 TASH developed a ‘National Agenda’ of issues that have serious human rights implications and the organisation focuses its research work, advocacy and lobbying in these areas:

- Inclusive education
- Employment
- Community living
- Diversity and cultural competency
- Human rights.

European Disability Forum

<http://www.edf-feph.org/>

The European Disability Forum is a cross-disability, independent NGO that represents the interests of 80 million Europeans with disabilities. EDF is the only European platform run by persons with disabilities and their families⁷³. The organisation is funded by the European Commission. On their website members are described as “disabled people and the parents of disabled people unable to represent themselves are the decision makers”. Members are self-advocates who campaign for the right of people with disabilities to be fully involved in the European policy-making process. There is an emphasis on building a strong network through building alliances with organisations who share the goals of EDF.

The organisation has a focus on campaigns. Active campaigns at the moment are freedom of movement (especially through a universally accessible environment across the EU), European comprehensive disability specific legislation to protect against discrimination across the EU and the creation of an implementation and monitoring mechanism for the UN CPRD.

Structure

EDF has numerous member organisations reflecting a broad geographical base and a wide range of concerns across the European disability movement. There is one national disability umbrella organisation from each European country and from Iceland and Norway. People with Disability Ireland (PwDI) is the Irish member organisation.

⁷³ <http://www.edf-feph.org/default.asp>

Inclusion Europe

<http://www.inclusion-europe.org/main.php?news=ok>

Inclusion Europe is an umbrella organisation representing over 60 societies of persons with intellectual disabilities and their families across Europe⁷⁴. The Irish member is Inclusion Ireland.

Inclusion Europe is funded by the European Commission and has a role in influencing European policy according to the needs of people with intellectual disabilities, their families and their organisations. The organisation is active in several policy areas specifically:

- Inclusive Education
- Community Living
- Social Inclusion
- Self-advocacy
- Non-discrimination
- Human Rights

Inclusion Europe maintains close contact with the European Parliament, the European Commission, the Council of Europe, European NGOs and national governments.

The European Platform of Self-Advocates (EPSA) is a part of Inclusion Europe and consists of organisations of self-advocates. EPSA meets at least once per year. A Steering Group of five self-advocates runs EPSA. Those five self-advocates are elected at the EPSA General Meeting taking place every two years. They meet several times a year and work, with the help of the self-advocacy Officer of Inclusion Europe, to implement the work-plan decided at the EPSA General Meeting. The 'Union on the Hill' self-advocacy group (supported by Inclusion Ireland) are members of EPSA.

⁷⁴ <http://www.inclusion-europe.org/main.php?lang=EN&level=1&s=80&mode=section>

Appendix 3

Individuals consulted

Julie Byrne	National Institute of Intellectual Disability
Deirdre Carroll	CEO Inclusion Ireland
Caoimhe Gleeson	HSE
Seamus Greene	Director, National Parents and Siblings Alliance
Charlotte Knight	Former Coordinator Citizen Advocacy Dublin project
Helen LaHert	Citizens Information Board
Bairbre Nic Aongusa	Office for Disability and Mental Health
Bridin Ni Dhonnghaile	Department of Justice and Equality
Colette Nolan	CEO, Irish Advocacy Network
Anne O'Donnell	Citizen Participation Unit, Department of Health
Marie Wolfe	Self Advocate
Mairide Woods	Citizens Information Board

Appendix 4

Framework for consultation

Met with:

Contact details:

Date:

Draft Framework/Discussion Guide for Consultative Meetings

1. Briefly describe your organisation's current role/offering
2. (As relevant) On the basis of your experience to date, is there anything you would do differently in designing your service?
3. What do you consider as the most critical needs of people with intellectual disabilities in securing their rights and entitlements, and the appropriate conditions to achieve self-actualisation?
4. Can you suggest ways in which people with intellectual disability can be supported to achieve their rights and individual capacity deficits overcome?
5. If there were to be an effective national service user advocacy initiative for people with intellectual disability, what would it look like? What particular features should it have?
6. Can you suggest some dos and don'ts?
7. Would you see a role for citizen advocacy to support people with intellectual disability and how would you guard against it becoming paternalistic?
8. Where would a service user advocacy initiative reside? Attached to an existing organisation or would it be better located in a new (or neutral) space?