

## **Autism self-advocacy in the Netherlands: Past, present and future**

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### **Abstract**

This article presents the results of participatory research into the roles and practices of autistic self-advocates in the Netherlands, and the outcomes of their activities. It discusses the history of Dutch autism self-advocacy, situating it within the history and practices of self-advocacy internationally and the socio-cultural context of the Netherlands. Particular reference is made to Judi Chamberlin's model for building effective self-advocacy organisations. Key findings include the scope of significant achievements, and the identification of barriers to efficacy in the areas of governance, personal and organisational capacity, relationships with other organisations, and coalition-building. The research concludes by considering what practices could serve to build increased capacity and efficacy, based on the experiences of these and other self-advocates.

**Keywords:** autism, Asperger syndrome, advocacy, self-advocacy, history of disability, Netherlands

### **Acknowledgements:**

The authors acknowledge the support of Disability Studies in Nederland and Prof. Geert van Hove towards completion of this project.

### **Funding:**

Disability Studies in Nederland receives support from RevalidatieFonds, Fonds VG, NSGK, Stichting SPZ and MEE Nederland.

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### **Introduction**

Self-advocacy by people with disabilities is often posited as a crucial stage in the development of more inclusive practices and cultures (Pelka 2012). Self-advocacy by autistic adults has emerged relatively recently, as professionals or parents have been positioned as speaking for people with autism (Waltz 2013.)

Self-advocacy takes different forms depending on its context and location. For example, Shakespeare (1993) notes key differences between the actions and demands of UK and US self-advocacy organisations, and Chamak (2008) contrasts self-advocacy practiced by autistic adults in France with French parent-advocacy and autism self-advocacy in the US.

### **Scope of research.**

This research investigates the practices, roles and results of autistic self-advocates in the Netherlands. It sought to gain and analyse information about personal motivations, key sources of information and support, forms of organisation, goals, factors that facilitated successful self-advocacy, barriers to self-advocacy, and outcomes. It documents the history of Dutch autism self-advocacy, situating it within the Dutch socio-cultural context and autism self-advocacy internationally.

Judi Chamberlin's discussion of effective self-advocacy practices by people seen as having mental health difficulties (1978, 1990) provided a key reference point. Autism is often addressed within the mental health system, and autistic people face similar institutional

challenges to self-advocacy. Chamberlin (1990) noted that development of the former psychiatric patients' movement included:

- Writing and publication of individual narratives by former patients
- Creation of former patients' groups (distinct from mixed groups that included professionals)
- Consciousness raising: sharing personal experiences and insights
- Development of national coalitions
- Collective self-help action projects, such as organising support groups, advocating for hospitalised patients, lobbying for changes in laws, public speaking, publishing newsletters, and developing creative ways of dealing with ex-patients' experiences
- Participation in forums where decisions were made, such as commissions and conferences
- Developing self-help alternatives to mainstream mental health services
- Through collective advocacy, strengthening individual self-advocacy skills

Chamberlin's model of the trajectory towards effective self-advocacy captured varied forms and outcomes. Other authors have analysed the typology of self-advocacy groups (Crawley, 1990), the relationship between self-advocacy organisations and professional advisors (Worrel, 1987 and 1988), and the impact of models of disability on self-advocacy practices (Goodley, 1997). Our choice to use Chamberlin's model as a comparator emerged from initial research, which revealed that autism self-advocacy in the Netherlands had not developed within established groups of patients or clients, or via facilitation by non-autistic advisors, but autonomously and with diverse personal and community goals and outcomes. Chamberlin's model, which described self-advocacy practices also developed via self-organisation, appeared most likely to capture the full range of individual and collective motivations, experiences, activities and results. This research demonstrates ways in which autism self-advocacy in the Netherlands parallels or departs from this model.

### **Terminology.**

We have chosen to use “identity-first” language (autistic adults, autistic self-advocacy) to respect the stated preferences of many adults who have an autism-spectrum diagnosis (Kenny, et al., 2015), and particularly those who identify as self-advocates (for example, Brown, 2015). Some autistic self-advocates argue that ‘people-first language’ further medicalises autism, which they often—but not always—position as a core part of their identity rather than something they ‘have.’ We have also, however, attempted to use the preferred terminology of our respondents, which included both identity-first and people-first language.

In the Netherlands, the type of self-advocacy researched in this project is called *belangenbehartiging*: ‘protecting one’s interests.’ Related concepts, including empowerment, *zeggenschap* (having a say in decision-making), and *medezeggenschap* (joint decision-making) relate mainly to activities within the health and care systems.

There are also formal forms of self-advocacy within Dutch facilities and services, such as *cliëntenraden* (client’s councils, a form of *medezeggenschap*), *cliëntenverenigingen* (client’s associations) and *patiëntenverenigingen* (patient’s councils). Except as noted, research participants said they were not involved in these.

## **Methods**

This article is derived from participatory qualitative research, which proceeded in three phases. It began with a deductive phase, in which researchers undertook a literature review and then used information gained from this and from personal knowledge to develop themes to investigate. We employed a systematic search of journal databases and university library catalogues using key terms such as disability+self-advocacy, autism+advocacy, and

autism+self-advocacy; we then extended the scope of research by following up references in sources initially identified. Second, eight Dutch self-advocates who identify as people on the autism spectrum were interviewed. In a final phase, interview texts were analysed and further contextualised through additional document-based research and discussion.

The team was comprised of four co-researchers—two with an autism-spectrum diagnosis, two without. A fifth co-researcher provided advice and assistance. Co-researchers with autism were academically qualified and worked on an equal basis with non-autistic researchers regarding discussions of study design, method, sample, parameters, ethics, processes, and analysis. Our analysis was greatly enriched through this intersubjectivity. We felt this was especially important, given that much autism research has not incorporated the valuable perspectives of autistic people themselves (Milton, 2014).

We used a semi-structured interview format, with attention to the communication style and preferences of people on the autism spectrum. Questions covered a range of topics, including individual motivations, activities, barriers and successes. Participants were asked to comment on a variety of autism self-advocacy practices and organisations as well as their own work. The semi-structured format provided space for participants to also discuss matters researchers may have otherwise missed or that participants felt needed emphasis. Data has been secured and anonymised, and informed consent was obtained from all participants.

Interview transcriptions were coded using MAXQDA software according to themes derived in the first research phase. Each interview was then re-examined to uncover the diversity of views and experiences, expanding the thematic analysis. Co-researchers continually drew upon an extensive literature review and had access to additional published,

broadcast and unpublished material from or about autism self-advocacy organisations and activities in the Netherlands. Through analysis of individual discourses presented in interviews, we were able to identify how participants positioned themselves as self-advocates, how they constructed autism as an identity and autism self-advocacy as a practice, and how emphases and views varied.

### **Research respondents.**

Interviews were conducted with eight individuals who played key roles in the history of autism self-advocacy in the Netherlands, based on self-advocacy organisation records, personal knowledge, and further referrals from each person contacted. Individuals were approached who had been involved with promoting self-advocacy and/or setting up self-advocacy organisations. Some declined to participate or withdrew, so there was an element of self-selection. In addition, one co-researcher who has herself played a major role in Dutch self-advocacy was interviewed by another who has not, bringing the final total to nine.

All research respondents identify as people on the autism spectrum, and all but one has received a formal diagnosis. Some individuals preferred to remain anonymous, so for ease of discussion all are identified in the text by letters. The following chart provides basic characteristics of the group.

	<b>Formal diagnosis</b>	<b>Gender</b>	<b>Age</b>
A	Autism	M	40
B	n/a	M	47
C	Asperger syndrome	F	31
D	Asperger syndrome	M	46

E	Asperger syndrome	M	56
F	Asperger syndrome	M	49
G	Asperger syndrome	F	67
H	Asperger syndrome	F	34
J	Asperger syndrome	F	39

We believe this group to be broadly reflective of people with autism and intellectual abilities within the normal or higher range who have been involved in self-advocacy in the Netherlands since 1995. It includes both genders, spans ages 31 to 67, and includes individuals involved in more than one form of autism self-advocacy or self-advocacy organisation.

### **Literature review.**

This section presents a brief outline of the history and practice of disability self-advocacy and autism self-advocacy. Co-researchers sought to review the existing literature on disability self-advocacy generally, autism advocacy and self-advocacy specifically, challenges to autism self-advocacy, and the history and framework of disability self-advocacy in the Netherlands.

### ***Disability self-advocacy.***

Preceded by charity campaigns; self-organisation by physically disabled, Deaf and blind people; and advocacy by parent organisations, self-advocacy became more visible in the 1960s, for example within the Disability Rights and Independent Living (IL) movements in the US and UK (Fleischer and Zames 2001). Although the IL movement grew out of access problems experienced by people with physical disabilities, its discourse centred on self-

representation, self-determination and de-medicalisation of disability, and this was gradually extended to other impairment categories. The Centers for Independent Living that emerged from this movement promoted self-advocacy based on consciousness-raising, peer-counselling, and collective advocacy (ibid.).

In the IL movement, self-advocacy could include service-based advocacy (for example, advocating for access or changes to services), political or policy advocacy, or advocacy for self-determination in aspects of individual life such as positive identity formation, health self-management, de-medicalisation of disability, and social inclusion. At times these forms of self-advocacy were interrelated.

Self-advocacy has also been positioned as a set of skills (Griffin, Taylor, Urbano and Hodapp 2014), a way of interacting with outside agencies and institutions (Aspis 2002), or a role arising from assuming power to make personal decisions (Shapiro 1993; Bagatell 2007). Some authors equate other forms of individual resistance with self-advocacy, with particular relevance to individuals who are not permitted to enter into a negotiating position or who are subject to institutional control (Chamberlin 1998; Baggs 2005).

Most self-advocacy research places self-understanding, knowledge and voice as essential components. Self-understanding may include identity formation as well as developing an understanding of personal medical, educational or social challenges. Knowledge required may include legal rights, communication techniques, and information about particular systems one needs to engage with. Finally, a self-advocate must have the means to communicate their ideas, choices and wishes. In each of these areas, people may act independently or with support.

Collective advocacy refers to self-advocates working together on issues they find important, such as service provision, public policy, legal rights, or access. This may occur through Disabled Peoples Organisations (DPOs), less formal local or online groups, or collective public actions. Chamak (op cit.) and others situate collective self-advocacy within the context of new social movements. Crossley and Crossley (2001: 1484) discuss how collective self-advocacy for people with mental health diagnoses potentially transforms both the subject and object of activity:

*Each individual case of mistreatment or injustice is now perceived and interpreted in terms of a generalised and categorical conception of 'the mental health system'. The generalised 'we' is oppressed by a collective 'them' or even an impersonal 'it'.*

A third form is representative advocacy: the use of professional or non-professional advocates to speak on behalf of disabled people who are said to be unable to fully understand or take part in decision-making: for example, on behalf of children or people with a severe intellectual disability. Representative advocacy may take place with or without a formal finding of incapacity, and sometimes without the person's full consent or participation (as in the case of 'best interests' proceedings.) It should not be confused with a disabled person who represents a DPO by bringing the views of its members to a public forum.

### ***Autism advocacy.***

The term 'autism advocate' is most typically used in the English-speaking world to refer to representative advocacy: a parent or professional who advocates for services, policies or laws they believe will be helpful to an autistic family member or people with autism generally. This is exemplified by the documents titled 'Advocacy' published by Autism

Speaks (2014a), which describes itself as ‘the world’s leading autism science and advocacy organization’ (Autism Speaks 2014b) but is run entirely by non-autistic people.

Some adults with autism are also described as, or use the title of, ‘autism advocates.’ These are generally individuals, such as Temple Grandin or Jim Sinclair, who speak or write not only about their own experiences but also advocate for service, system or social change, ostensibly on the behalf of people with autism generally, although without any formal process of soliciting their views.

### *Autism self-advocacy.*

Especially in its birthplace of Berkeley, California, the IL movement had close ties with the psychiatric survivors’ movement, which championed self- and collective advocacy for people labeled as having mental health conditions. It is through this connection that perhaps the first known instance of autism self-advocacy emerged, although the terminology differed, as ‘childhood schizophrenia’ and ‘autism’ were used interchangeably into the 1970s.

Ted Chabasinski was a six-year-old foster child when he was delivered to Dr Laretta Bender’s childhood schizophrenia programme at Bellevue Hospital in the 1940s. Bender, still sometimes lauded as an autism treatment pioneer (Feinstein 2010), subjected Chabasinski to repeated rounds of electric shock treatment (ECT.) While at Bellevue, he was also the victim of repeated physical and sexual assault. When his ‘condition’ did not remit, he was sent to a state hospital, where he spent the remainder of his childhood, often dosed with psychiatric medications. However, Chabasinski survived the experience and went on to be instrumental, with his then-wife Judi Chamberlain, in building the psychiatric survivors’ movement. (Chabasinski 2012).

There are other pioneers whose names are not known because they came forward through the self-advocacy movement for people with intellectual disabilities, or because their activities took place in extremely difficult and individualised circumstances (Ward and Meyer 1999).

People First, a group that began in the US state of Oregon in 1973, originated more organised self-advocacy activities for people with intellectual disabilities. Similar self-advocacy groups have proliferated worldwide over the past 30 years. These have been involved in deinstitutionalisation, and in supporting people with intellectual disabilities to assume the role of independent citizen (ibid.; Redley and Weinberg 2007). Some who became self-advocates through People First or similar organisations have been people with autism (Ward and Meyer op cit.).

Eyal et al. (2010) make a strong case for the rising prevalence of autism diagnosis and the formal establishment of a wide-ranging autism spectrum as an outcome of deinstitutionalisation. They argue that this broad category was constituted to recapture a large group that lay between and intersected with the categories of mental ill health and intellectual disability by a new matrix of professional practices, parental discourses, therapies and institutional forms. In this analysis they write, in relation to Lorna Wing's concept of the autism spectrum, that 'the choice to retain the separate label "Asperger's syndrome" revealed an astute awareness of the forces of demand put into motion by deinstitutionalization... a back door into the world of autism therapy and advocacy' (225: 'advocacy' here refers to parent-advocacy.)

However, Eyal et al. err in placing autism self-advocacy as a process driven by the needs of parent-advocates, locating autism outside the trajectory of disability movement history even as they reference it. People with an autism spectrum diagnosis have often also negotiated the mental health or intellectual disabilities system; able individuals may encounter disability rights activists or coverage of them, or Disability Studies texts. They may also have a lifetime's experience of the efforts of others to normalise them, self-normalisation attempts, and complex identity negotiation (Baines 2012).

Baines (ibid.) highlights the difficulties isolated young people with autism face as they try form stable identities in mainstream environments. The pressure to fit in through extremely effortful social performance can be devastating, as many autistic authors have described in autobiographical accounts (for example, Williams 1992; Willey 1999; Nazeer 2007). However, making links with other young people or adults has been historically difficult. Some parents do not inform children that they have an autism spectrum diagnosis, and the standard advice for decades has been that integration in mainstream education and continual exposure to non-autistic peers is crucial for the socially valorised normalisation process (Waltz 2013). Individuals diagnosed as adults often have additional experiences of previous wrongful diagnosis or social failure (for example, Meyerding 1998).

In keeping with Chamberlin's framework, Dekker's seminal 1999 paper begins the history of organised autism self-advocacy with the publication of personal narratives by adults with autism. Although the first of these (for example, Williams 1992) were published with a non-autistic audience in mind, they also reached other autistic adults.

Ward and Meyer (op cit.) and Dekker (op cit.) have noted the key importance of the Internet in bringing autistic adults together in friendship circles, leading to consciousness raising and self-advocacy, and corresponding to the second and third activities in Chamberlin's list.

For at least some self-advocates with autism, the Internet is their only or primary avenue for self-advocacy. Specific forms of online self-advocacy have emerged, such as individual communications with the world via blogs, vlogs, and self-produced films (for example, Arnold 2014; MeneerDeAardappel 2014), and using the Internet to orchestrate collective advocacy via (electronic) letter-writing or adverse publicity campaigns, a tactic adopted by the US-based Autistic Self Advocacy Network (ASAN) to combat misrepresentation of autistic people in the media or by service providers. Other organisations, such as Aspies for Freedom (now defunct), have used the Internet to organise protests and even to assist members to leave residential services they experience as oppressive. However, not all people with autism find using the Internet easy or pleasant.

Self-advocacy can also contribute to positive identity formation and personal development, as noted by Goodley (2000), Beart, Hardy and Buchan (2004) and others. For people with autism, whose sense of identity as autistic people or even as human is so often contested, denied or opposed by systemic practices (Bumiller, 2008), identity formation may go hand-in-hand with achieving practical goals. Townson et al. (2007) researched the development of advocacy for people with autism. They found four overarching areas in which advocacy/self-advocacy was desired by participants:

- *late diagnosis and lack of support services;*
- *unfortunate experiences within the system of care;*
- *feelings of not belonging and issues of identity;*

- *barriers to communication and sensitivity* (ibid., 527)

Although research participants expressed an interest in (self-)advocacy, Townson et al. found they lacked access, had little awareness of advocacy and rights, and found it difficult to fit into what was already available (ibid., 530). These priorities and barriers point to ways in which individual and systemic issues may be intrinsically linked. For example, lack of understanding by others may be seen by self-advocates as leading to inadequate services or abuse. As in Chamberlain's model, self-organisation and consciousness raising give rise to the competencies needed for effective action.

Of course, identity formation is also influenced by cultural norms promulgated by families, schools and other institutions, and by socio-medical constructs such as diagnostic systems. Hacking has also highlighted the 'looping' effect through which individuals construct specific forms of disability identities in relation to medical/professional literature (2006) and published autobiographical accounts (2009), identifying with what they have read and creating new ways of being a person based on emerging classifications. This process presumably extends to narratives shared through self-advocacy groups. And for adults with autism, there are choices to be made regarding how one will interact with autism as a diagnosis or identity; these choices may change over time. As Hacking notes, in the 1980s Temple Grandin (cited in Hacking 1999, 121) described herself as a 'recovered autistic,' while today she is simply 'autistic' (Grandin 2013). Self-advocacy takes place within the habitus of autism discourse, but also plays a part in transforming it (Crossley and Crossley op cit.).

### ***Challenges to (autism) self-advocacy.***

Whenever a practice challenges vested interests, it may be opposed or coopted. Autistic self-advocates have been attacked through doubts published about the veracity of their autism diagnosis (for example, Anonymous 2014), insinuations that they are mentally ill (ibid.), or suggestions that high-functioning individuals are so different from others with autism that their opinions do not have value (for example, Stagliano 2010). Chamberlin (1990) notes that such processes can even occur within self-advocacy organisations, because members will have absorbed the same societal beliefs about disability.

There is almost always tension around the exercise of self-advocacy outside of proscribed boundaries (for example, outside of formal clients' councils), and around self-advocacy by groups perceived by some as incapable of voice or agency, as has historically been the case for people with autism (Waltz 2013).

The form and language of autism self-advocacy may also be adopted by service providers and governments, at the same time as these constrain what can be said, who can say it and, most importantly, whether and when self-advocates can exert power (Aspis 1997; Redley and Weinberg 2007). Self-advocacy can also be co-opted as a way to further institutional objectives:

*...it is entirely possible for a multitude of empowerment practices to be implemented without empowerment being achieved. Empowerment in everyday life cannot happen unless the structures and institutions of civil society are themselves empowering, rather than constraining.*

(Ramcharan et al. 1997, 253)

Finally, self-advocates may face additional barriers: lack of funding or time, a shortage of strategic expertise, burn-out, or access factors related to their disability.

### ***Self-advocacy within the Dutch cultural context.***

Commenters on Dutch culture (for example, White and Boucke 1989) have noted that the strong focus on talking problems through until consensus can be found—the so-called “polder model”—encourages conformity on an individual level. The popular saying *doe even normaal!* (just act normal!) and its disapproving converse, *niet normaal*, are common expressions of policing behaviour. This places people with innate differences at a distinct disadvantage.

Disability self-advocacy in the Netherlands has a long history, however, particularly for visually impaired, hearing impaired and physically handicapped people (Brants, van Trig and Schippers, forthcoming). Goals tend to involve seeking a seat at the table, not control. In addition, forms of care for disabled people (separate schools, work and housing for many decades, giving way somewhat to a comprehensive welfare state in the 20<sup>th</sup> century) have tended to work against a ‘rights-based’ approach. For this article, we looked at self-advocacy by people labeled as intellectually disabled, mentally ill, or autistic.

Kees van der Pijl (2012) has written a short, informal history of intellectual disabilities advocacy in the Netherlands, covering the national organisation Platform VG and its predecessors. This begins with parents organising in the 1950s, sometimes in tandem with care providers (which often had sectarian religious affiliations), and several efforts at forming national organisations along diagnostic lines. His account includes some information about the Nederlandse Vereniging voor Autisme (NVA), a parent organisation created in 1978. He states that the NVA has not usually participated in cross-disability networks. The NVA currently has 14,000 members, with 300 volunteers and a smaller number of full-time employees in 11 regional chapters

Van der Pijl notes that *self*-advocacy for people with intellectual disabilities is relatively recent in the Netherlands. The trajectory he maps is similar to that described by Wehmeyer, Bersani and Gagne (2000). He cites Landelijke Federatie van Belangenverenigingen (LFB) Onderling Sterk ('Strong Together') as the first viable national federation of local groups, followed by another national coalition, Vraagstuk ("Apt Question"). Vraagstuk imploded and has been folded into advocacy organisations that may also support self-advocacy in the sense of moving towards choice, voice and personal budgets, e.g. Stichting Perspectief. He notes that changing directions in government subsidy have had a powerful role in how parent- and self-advocacy groups have operated.

Local Onderling Sterk groups and the LFB still exist, and are similar to the People First model. Some members take part in formal collective or self-advocacy activities, such as being part of local government advice panels, and the groups also encourage and sponsor social and self-empowerment activities, such as co-developed person-centred planning. People with average or higher intelligence and autism have organised themselves separately.

Currently, a large umbrella organisation, Ieder(in), links Dutch self-advocacy groups and also has connections with EU disability campaigns. The NVA is a member, but no autism self-advocacy organisation is.

For a long time, Dutch children and adults with autism were treated as if mentally ill. Currently people with autism who experience difficulties must often look to the mental health (*Geestelijk Gezondheidszorg* or GGZ) sector. GGZ Nederland defines autism as a *stoornis*

(disorder) characterised by areas of deficiency (GGZ 2014), in line with the medical model of disability.

Within the GGZ, a movement emerged in the 1970s that emphasised patient participation. Petra Hunsche states that it achieved ‘a progressive Dutch (polder) model of client-participation’ (2008, 255), which included treatment reforms and patient councils. Forster (1998) also notes that its form reflected the ‘general participative political culture’ of the Netherlands (159), shaped by government funding initiatives and legislative frameworks.

Influenced by sociologist Erving Goffman, anti-psychiatry pioneers like Thomas Szasz, Dutch authors and the general anti-authoritarian mood of the times, the psychiatric patients’ movement in the Netherlands was often held up as a model internationally (Weinstein 2010). For example, it was documented in the film *Speaking From Experience* (Basset 1985), used by organisers setting up patients’ groups and councils elsewhere (Survivors History Group 2014).

Hunsche (op cit.) notes that GGZ reforms in the 1980s and beyond included moving from institutional care to small-scale facilities and support for independent living. Client councils are now part of the institutional GGZ system, and some pioneering self-help projects remain, although a new law moving decision-making to the local level in 2015 may introduce changes.

### **Research findings: Autism self-advocacy in the Netherlands**

This section of the paper will sketch the history of autism self-advocacy as described by research participants; the information provided during interviews has been cross-checked with documents and contextualized as possible with reference to other sources.

Self-advocacy-centred reforms referred to in the literature review above did not necessarily include people with autism, as there are still many residential institutions in the Netherlands for people with intellectual disability and/or autism, and far fewer instances of corresponding self-advocacy within these facilities. This mirrors the situation elsewhere. For example, Wehmeyer, Bersani and Gagne (op cit.) position autism self-advocacy as about making choices about services and supports, a process that should be guided by (non-autistic) service providers. This places able adults with autism in an object position, in contrast to Ward and Meyer (1999), who claim self-advocacy as a potentially emancipatory practice, with positive identity formation a crucial first role. As Dekker (1999) said: ‘culture requires self-advocacy.’

The largest Dutch autism organisation today is not a self-advocacy group but the NVA. Although adults with autism can join the NVA, and three of the individuals interviewed have worked in conjunction with it, our research participants noted that they are at odds with at least some NVA activities and positions. As D said, ‘Sick, weak, pathetic, care, in need of care... that is the undertone of what I found with the NVA.’ Others said they were not perceived as equals by the parents’ organisation. ‘If I get 10 minutes speaking time at the NVA congress, as an expert by experience, and all the other people are given 20 or 40 minutes to speak, then by definition we are being treated differently,’ said E.

The gulf between the NVA and self-advocates is huge. ‘You have one mountain, which is the... parents organisation, and you’ve got the other mountain, which is the people

themselves running things, and... there aren't enough bridges between the two,' said C. Participants noted that parents and professionals dominate how Dutch society responds to autism through image-making and participation in official activities such as advising government. Changing this was an important impetus for the development of self-advocacy by able autistic adults.

However, while the first organised effort at autism self-advocacy in the Netherlands began in the mid-1990s, it was directed towards the English-speaking world rather than nationally. A had been involved in early Internet activities, such as FidoNet and Usenet, and joined the ANI (Autism Network International) list. ANI was started by Jim Sinclair and other autistic adults who left the St John's Autism List for parents in 1992 (Dekker op cit.). In reaction to some personal issues on ANI, A and another autistic adult started the InLv (Independent Living) mailing list in 1996, and A then set up the *alt.support.autism* Usenet group in 1998. InLv eventually included an extensive Web site with discussion forums on a variety of subjects.

A stated that as far as he was aware, autism self-advocacy in the Netherlands was 'nonexistent' at that time. Although a university psychologist tried to steer him towards residential group therapy, he avoided the GGZ system where, he added, 'I suspect that clients didn't have much of a say, at all.'

His motivation was first 'trying to figure myself out,' he said. 'My preferred method of doing that was... to get in touch with others online. And it took me awhile before I got comfortable actually meeting others.' All other respondents also described self-advocacy as

having been self-initiated: none reported being introduced to self-advocacy through a service, therapy or training/education programme.

In 1997, A traveled to the US to speak at a Society for Disability Studies conference. He described this period as ‘a really intense time of connecting with others and exchanging experiences, and figuring out my own identity while others were figuring out theirs.’ Building a stronger self-image was key: ‘I think what many people got out of it was the feeling of being understood for the first time in their lives.’ A and other self-advocates he corresponded with were aware of the disability rights, psychiatric survivors and independent living movements, and some made explicit links between these and their own activities and goals (ibid.). However, English-language books and essays about autism self-advocacy or identity were not cited as particularly important in this formative process.

A eventually started two Dutch-language lists, the AS-Kring for autistic people and A-Spectrum, which was open to parents and professionals. J was a member of the AS-Kring at that time:

*In the Netherlands, the AS-Kring is where it happened. There is the core group of active people who write a lot and influence opinions. We discuss both our own lives and the general situation in the Netherlands regarding autism. We share our outrage: at this time, there is nothing for able adults with autism. Nothing planned, nothing organised, no information available. Autism is only about children and people with intellectual disabilities. We feel unheard and invisible; our needs are not met. The only organisation is a parents' association (NVA), for whom we seem to not exist.*

In 1999, A transferred co-ownership of the lists to another autistic adult, and provided computer support to individuals forming the first self-advocacy organisation, AutSider, a process that took two years (1999-2001).

Autsider's Web site attracted 13,000 visitors in 2000 (Valk 2000), but internal divisions prevented it from becoming the active organisation its founders had hoped for. A group of four AS-Kring members therefore decided to start their own organisation. J noted that some members of the group already had experience of organising via student and political movements, and they were able to call on the energy and idealism of youth. This project resulted in Personen uit het Autisme Spectrum (PAS), founded in 2001, which remains the largest autism self-advocacy organisation in the Netherlands, with over 500 members.

PAS's organisers were also in touch with a slightly older autism self-advocacy group in Belgium called PASS, and originally adopted their name. A book of personal narratives, *Autisme Verteld* (Schiltmans 2002), emerged from this collaboration.

For several years, although PAS was a self-organised group it attempted to work alongside or within the NVA. However, the NVA brought parents and professionals together in forms of discourse about education, therapies, and family support that generally relied on a view of autism as something that affects primarily children. Parent and professional members were concerned with ameliorating lifelong disability and placed themselves as decision-makers. PAS members sought self-determined solutions leading to good adult lives.

'The NVA saw us as a threat,' said J. 'It felt its existence was threatened. If people with autism began to organise themselves, that could erode the NVA's foundations.' In addition, she noted, PAS members were energetic and wanted to set up events and programmes right away. The NVA's internal structures were bureaucratic and slow-moving. Rather than supporting PAS, the NVA was perceived as offering little practical help, sometimes standing

in its way, and being more interested in corporate brand visibility than the quality of its offer to autistic adults.

Indeed, its initial proposal was that the NVA would appoint PAS board members and approve any public messages. J and B were at that time PAS directors, and F was also involved in the negotiations. ‘PAS could not agree to this administrative structure,’ J said, referring to proposed membership administration and financial agreements, ‘but it took another four years before we had gathered enough courage to pull away from the NVA and formally set up as PAS with our own statutes.’

Lack of autistic adults on the NVA board was a particular flashpoint. ‘For us, it always felt like they want our people and resources (and our time and energy), but gave nothing in return,’ J said.

The NVA’s internal turmoil during this time presented further complications. The relationship between national and regional branches was turbulent, and a new director and management consultants arrived.

Problems did not disappear when PAS declared full independence, however. Without the NVA battle as a focus, internal divisions grew, even as membership grew rapidly. With hundreds of members to support, there was additional pressure but less forward momentum from the centre. Between 2008 and 2010, several members (including J) reached the point of burn-out.

Other PAS members chose to form or join different or competing organisations. These included Stichting AsocialeKaart, which since 2011 has run social events ('Iets Drinken') for adults with autism in several Dutch cities and towns, and Autisme Ten Top (ATT), currently focused on employment issues.

Some, such as F, have gravitated towards local action. 'I think self-advocacy done the other way cannot work,' he said. 'The most effective position is on the local level. That is the point of engagement where care and adjustments must be sorted out.' This tactic may have increased relevance for self-advocates from 2015, when all support decisions will be made locally. Others, including E, have welcomed new opportunities to work within the NVA.

Nevertheless, PAS has continued its informational, advisory, and social activities, and over the years PAS special-issue groups have worked in areas such as housing.

In the past two years, formal self-advocacy by autistic people within an institutional context seems to be getting its wings. C is involved with two *ervaringsraden* (groups of *ervaringsdeskundigen*: 'experts by experience'). One is affiliated with the Dr Leo Kannerhuis, a major service provider, the other, Vanuit Autisme Bekeken (From the Autism Perspective), provides information and advice for service providers and government bodies.

## **Research analysis.**

When asked to discuss their achievements as self-advocates, most participants were self-deprecating. For example, one said PAS had ended up as ‘a social club,’ and others had voted with their feet, moving on to new projects or retiring from public self-advocacy.

It is difficult to square the disappointment expressed by research participants with the evidence collected by our team showing that autism self-advocates have made significant progress. Over 20 years from the initiation of autism self-advocacy in the Netherlands, research participants described a variety of current or past activities, including writing, publishing or presenting personal narratives, advice, and informational documents; consciousness raising; creation of self-advocacy groups for people with autism, including local and national organisations; successfully carrying out self-help projects (for example, Autism Ten Top’s employment campaign and PAS’s housing group) and, slowly, having influence on the national narrative about autism and at the policy level. Also, despite frustration, disappointment, and the risk or reality of burn-out, research participants said they have strengthened their individual self-advocacy skills through participation in collective advocacy.

Longhurst (1994) carried out a wide-ranging study of self-advocacy in the US. He found that groups differed widely, and only 15 percent had engaged with the more complex activities in Chamberlin’s scheme: collective advocacy, participation in policymaking or creating self-help alternatives to services. Most primarily supported individual self-advocacy and social activities.

Funding, support and governance play a role in organisational efficacy. Caldwell (2010) researched leadership development as a way to surmount barriers to successful self-advocacy

by people with developmental disabilities, including autism. Issues identified include limited access to formal training, lack of regard by ‘partner’ organisations for support and other needs of disabled people, and deliberate blocking.

All of our respondents said that having autism had been beneficial for their self-advocacy work, conveying focus, determination and rationale. However, some saw difficulties with communication and resistance to change or to other points of view as a potential negative contribution. Caldwell’s research, which has influenced the leadership and capacity-building work of ASAN in the US, offers a potential way through that builds on strengths. Access to appropriate training resources and useful systems for managing internal difficulties at Board level could be valuable. It may be important to develop these resources and capacities within the autistic community itself, however, rather than bringing them in from outside consultants.

For example, F suggested that there could be a role for expert coaching to improve governance. ‘However, I think a high percentage of those qualified to coach [at Board level], people with the right qualities, are those who see autism as a limitation, not as a quality,’ he said. ‘They do not see us as equal persons.’ Chamberlin (1990) noted that mixed membership led to watered-down, reformist goals in ex-patients’ groups. Systems would be needed to ensure coaches do not assume power or manipulate policy.

The problem of educating partners and ensuring they stay within bounds extends from organisations like the NVA to formal forms of self-advocacy within health and care, C added:

*You have to just be so careful. I’m chair of two [ervaringsraden] and I do notice the dangers that the organisations want to ... say, we now can defend what we’re doing because you know, we’ve got now people with autism saying “yes we agree with that.” And every time I have to remind them that, no, these are twelve people with autism, and you cannot say that, because that’s putting way too much responsibility in our hands, and that’s the politics.*

E suggested that self-advocates could also encourage companies and community organisations to pursue culture change, as this has been helpful to raise understanding of other minority issues in the Netherlands.

Brunk (1991) found that self-advocacy produces gains valuable enough that institutions outside the self-advocacy movement should give it material and ideological support. Further, ‘collaborative development is going to be increasingly necessary, and if you don’t grab hold you will be left behind,’ warned D. Although past experience of trying to work with the NVA has left a bitter taste, increased clout may be gained via alliances. However, potential allies should be prepared to accept autistic self-advocates as equals—indeed, as ‘experts by experience’—and this may require internal education and consciousness-raising.

### **Conclusions.**

The Netherlands has a long history of formal self-advocacy within health and social care facilities. These forms of self-advocacy have generally not been rights-based, nor have they generally been extended to people with autism within health and care systems. Our respondents also suggested that many needs they identified for themselves, such as improved self-image and destigmatising autism, lay outside these systems.

Participants discussed barriers to effective self-advocacy. These included lack of funding and organisational support, and over-reliance on a small group of more able individuals, often leading to ‘burn-out’ or lowered effectiveness. In common with their counterparts elsewhere, they describe a ‘power struggle’ between autistic self-advocates and parent-professional

organisations. This has ranged from ignoring the needs of adults to attempting to co-opt the work and energy of self-advocates. Organisations that wish to support self-advocacy should therefore consider how funding, organisational help, and training could instead build capacity for self-advocacy.

Autistic self-advocates placed self-understanding, social contact, and changing the public image of autism as their most important goals. They described developing greater personal efficacy and skill as a result of their self-advocacy work. Self-advocates mostly pursued influence and self-determination rather than a rights-based agenda. Participants found community-building and collective self-advocacy to have been less successful—but not impossible.

The situation for adults with autism in the Netherlands has changed significantly because of self-advocacy. Successes sometimes happen quietly, and can take time to emerge. So while some participants said they felt people with autism still are not listened to or respected within Dutch health care, the GGZ now lists PAS ahead of parent-professional organisations as a good source of information and support for adults on the autism spectrum (GGZ, 2014b). There are now many local groups run by and for people with autism, offering primarily social activities. Some self-advocates continue to write and give lectures, and others persevere with advocacy within systems. A newly diagnosed Dutch adult today would not find it difficult to locate peers or accurate information, and could join or initiate campaigns more easily.

Autism self-advocacy organisations in the Netherlands have not yet made successful, lasting alliances with organisations of self-advocates who have other labels, such as people with learning difficulties, physical disabilities or mental ill health. And although some

respondents were familiar with or influenced by ideas from outside the Netherlands or Belgium, there are no strong alliances between Dutch autism self-advocacy groups and their international counterparts. In the UK and the US, such internal and external alliances have proven crucial to successful collective self-advocacy.

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