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Article

# “More Honoured in the Breach than in the Observance”—Self-Advocacy and Human Rights

Gabor Petri \*, Julie Beadle-Brown and Jill Bradshaw 

Tizard Centre, University of Kent, Canterbury CT2 7LR, UK; J.D.Beadle-Brown@kent.ac.uk (J.B.-B.), J.Bradshaw@kent.ac.uk (J.B.)

\* Correspondence: petri.gabor@gmail.com; Tel.: +44-1227-827373

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**Abstract:** Background: Since the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD), human rights have become central for disability advocacy. The CRPD requires that disabled people and their representative organisations (DPOs) have a prominent role in the implementation and monitoring of the Convention. However, the representation of people with intellectual disabilities or autistic people is still often indirect, carried out by parents or professionals. Methods: This is a qualitative research which looks at how self-advocates (SAs) with intellectual disabilities or autism participate in DPOs and how they see the role of human rights and laws such as the CRPD in their advocacy. Data was collected in the UK and in Hungary between October 2016 and May 2017. A total of 43 advocates (SAs and other advocates) were interviewed. For the analysis, thematic analysis was used. Results: findings indicate that most participants have limited knowledge of the CRPD and human rights. Human rights are usually seen as vague and distant ideas, less relevant to everyday lives. SAs may not feel competent to talk about the CRPD. The inclusion of SAs in DPOs is mostly tokenistic, lacking real participation. Conclusions: The CRPD can only bring meaningful change to SAs if they get full membership in DPOs.

**Keywords:** self-advocacy; intellectual disabilities; autism; learning disability; disabled people’s organisations; DPOs; disability movement; Hungary; United Kingdom; human rights; UN CRPD

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## 1. Introduction

Much has been written about disability rights and particularly about the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN General Assembly 2007): numerous academic and civil society accounts have been produced both nationally and internationally (García-Iriarte et al. 2015; Sabatello and Schulze 2014). This trend is not specific to disability rights—human rights legislation and human rights mechanisms have never been as elaborate and strong as today (Bantekas and Oette 2013). The amount of knowledge produced under the ‘human rights model’ (Degener 2014) is sharply growing including civil society accounts, monitoring reports, state bodies’ official statements and various indicators and statistics, which provide a wealth of information about how human rights of disabled people are respected or breached around the globe. Ten years after the ratification of the CRPD, such reports became central to understanding the lives of disabled people and it seems the progress in implementation is palpable everywhere. Our knowledge about the human rights of disabled people has never been so comprehensive and so detailed.

The voices of disabled people in the production of this knowledge are central within the disability rights movement (Degener 2016). However, not all disabled people have an equally strong voice. Little attention is being given to people with intellectual disabilities or autism within human rights literature and it is virtually unknown how they see the last ten years’ progress. For example, while implementation reports are usually developed by disabled people’s organisations (DPOs) or human

rights groups or state bodies, people with intellectual disabilities and autistic people almost never take a leading role in drafting such reports, let alone participate in drafting them. Organisations representing autistic people or people with intellectual disabilities are still led (with few exceptions) by parents or professional advocates while self-advocates with intellectual disabilities or autism remain weightless within ‘their own’ organisations.

It is rarely asked how much self-advocates know about the CRPD or other relevant international or domestic human rights instruments. It is unexplored what they think about the impact of the CRPD and other relevant laws, or if they think the human rights approach is useful for them at all. We also do not know how meaningful is their participation within the disability rights movement or how they are involved in implementing or monitoring the CRPD.

Based on empirical data from the United Kingdom and Hungary, the present article will focus on people with intellectual disabilities and autistic people who engage in disability advocacy (self-advocates). It will be appraised how self-advocates participate in the movement of disabled people, and how they think about human rights in general or the CRPD (and other laws) in particular.

DPOs often call on governments to involve them more in the implementation and monitoring of the CRPD; it is time to take a look at how meaningfully DPOs themselves can involve people with intellectual disabilities or autistic people within their own human rights advocacy.

## 2. Background

Self-advocacy is not only individual resistance to oppression or a group activity, but is part of the broader social movement of disabled people’s organisations. Although the term ‘disability movement’ is widely used in academia and in civil society (Goodley 2011; Shakespeare 2013), it must be stated that there is no common agreement on what the disability movement actually means (Beckett 2006), where its boundaries lie and what it means to members of the movement. When the ‘disability movement’ is mentioned, it usually means the looser or stronger alliance of those organisations that are controlled or managed by disabled people. Depending on national or international contexts, such organisations may represent one or more of the following groups: people with physical impairments, people with visual impairments, deaf people, people with hearing impairments, people with intellectual disabilities, autistic people, etc. Importantly, while acknowledging that self-advocacy is part of the broader disability movement (Aspis 1997; Mccoll and Boyce 2003), there are also salient differences and even tensions between groups of disabled people which must be explored in order to understand where self-advocacy stands today.

### 2.1. Self-Advocates in the Disabled People’s Movement

Despite the developments of disability advocacy in the global West and internationally, the marginalisation of people with learning disabilities within the movement has been observed by several authors (Aspis 2002; Campbell and Oliver 1996; Chappell 1998; Chappell et al. 2001; Dowse 2001; Garcia-Iriarte 2016; Goodley 2004; Stalker 2012). Critical voices demanding equal recognition of people with intellectual disabilities or autism in the broader disability movement have been heard since the 1990s.

For example, Chappell (1998) asserted that the voice of people with intellectual disabilities is largely missing both from the movement and from the academic discipline called disability studies, a view shared by others (Boxall 2002; Stalker 2012). Most researchers in disability studies have ignored the problems of people with intellectual disabilities (Ryan 2016), because there was too much focus on bodily impairments and intellectual disabilities are ‘located in the backwater of disability studies’ (Chappell 1998). When self-advocates get into leadership roles, their involvement may still be tokenistic (Beckwith et al. 2016).

An autistic self-advocate’s opinion exposes systemic fractions and power relations in the disability movement:

‘Any attempt by a group of disempowered people to challenge the status quo—to dispute the presumption of their incompetence, to redefine themselves as equals of the empowered class, to assert independence and self-determination—has been met by remarkably similar efforts to discredit them. ( . . . ) [they try] to deny that the persons mounting the challenge are really members of the group to which they claim membership. This tactic has been used against disability activists with learning disabilities and psychiatric disabilities as well as against autistic people.’ (Sinclair 2005)

Of course, the marginalisation of self-advocates is rooted in multiple factors and not only in the contesting interests of different groups. There are several reasons why joining the disability movement for people with intellectual disabilities is difficult. For instance, debates and arguments are difficult for them to follow, and the social model itself is too abstract for many self-advocates to understand and interpret it. Information about general knowledge available for the rest of society is limited, or inaccessible (Aspis 1997; Stalker 2012). Also, although progressive frameworks are becoming available (Arstein-Kerslake and Flynn 2016), people who are assessed to have ‘limited mental capacity’ are still systematically deprived of their legal capacity (Fundamental Rights Agency 2013; Simpican 2015) or voting rights (Priestley et al. 2016; Schriener et al. 1997) which makes it extremely difficult to exercise citizenship, agency or political activism. Furthermore, many self-advocacy groups work in relation to and rely on social services which makes it almost impossible for them to criticise systemic practices or more structural oppression (Aspis 1997; Buchanan and Walmsley 2006; Chappell et al. 2001; Dowse 2001; Goodley 2000). The relationship between collective and individual advocacy actions may also be controversial: self-advocates willing to act are expected to wait for meetings organised and decisions taken which many of them find difficult (Aspis 2002), and perhaps new, unorthodox ways of advocacy actions should be explored that suit people with intellectual disabilities or autistic people better (Dowse 2001).

There may be a ‘hierarchy of impairments’ in the movement where people with intellectual disabilities fight to be recognised as other than ‘stupid’ (Stalker 2012), exercising resilience not only in relation to the society of non-disabled people but also to their peers with physical or other impairments, because according to self-advocate Simone Aspis, people with other disabilities ‘are using the medical model with us’ (Campbell and Oliver 1996). It was also revealed that in the history of the disability movement such internal hierarchy has been present from the beginning.

‘ . . . I hate to say but there was a pecking order within the disability community, and people with a cognitive disability were on the bottom of that order. And so nobody wanted to associate with us.’ (Pelka 2012)

There are also distinctive features and needs that may differentiate people with intellectual disabilities from other disability groups. For example, personal experiences (as opposed to abstract concepts) are more important to them, because life experiences or concrete examples make things easier to understand (Boxall 2002; Stalker 2012). Also, while most disabled people identify with their label (‘blind’ or ‘deaf’), similar identification is often problematic for people with intellectual disabilities (Beart 2005; Chappell et al. 2001) which impacts their participation in the movement that expects them to accept a collective identity.

It also matters *who controls* DPOs. Parent-led organisations have always played an important role in intellectual disabilities (Goodley and Ramcharan 2010; Goodley 2000; Gray and Jackson 2002; Simpican 2015; Wehmeyer et al. 2000). Until today, it is still advocacy organisations founded and controlled by parents or professionals who often act as representatives of the ‘field’ of intellectual disabilities or autism. Tensions between autistic self-advocacy organisations and powerful charities led by professionals have been present in the US (McGuire 2012; Ne’eman 2010). In Britain, with the presence of ‘people first’ groups or other self-advocacy organisations, this substitute representation is perhaps more balanced and self-advocacy enjoys a certain level of visibility. However, the dominance of parents is still unchallenged internationally: it is parents or professionals who represent people with

intellectual disabilities in several 'national disability councils' across Europe, for example in Greece, Germany, Hungary, Italy, Latvia, the Netherlands, Norway, Poland, and Spain ([European Disability Forum 2016](#)). It is also parents and professionals who control international advocacy organisations such as Autism Europe or Inclusion Europe, although international self-advocacy networks are gaining more importance ([Epsa 2017](#); [Nagase 2016](#)).

In the first decades of autism advocacy, it was also parents and families that established advocacy organisations ([Bagatell 2010](#); [Balázs and Petri 2010](#); [Chamak and Bonniau 2013](#); [Kemény et al. 2014](#); [Sinclair 2005](#); [Waltz 2013](#); [Ward and Meyer 1999](#)). Autistic self-advocates only became visible from the late 1990s onwards ([Waltz 2013](#)). The problem with representation by parents in advocacy is summarised by autistic self-advocate Jim Sinclair ([Ward and Meyer 1999](#)):

'Parents and professionals acting on behalf of us is not the same as us, speaking of ourselves. Parents and professionals are more concerned about taking care of disabled people, than with freedom and rights for disabled people.'

Canadian autistic self-advocate Michelle Dawson even argued that the national organisation:

'Autism Society Canada should change its name to reflect its real objectives, membership, and governance. The new name should indicate that this organization is by and for parents, e.g., Parents of Autistic Children Canada'. ([Dawson 2003](#))

## 2.2. Self-Advocacy and the Human Rights Approach

Since the adoption of the CRPD in 2007, and other human rights legislation such as national anti-discrimination laws, much of disability advocacy uses the language and concept of human rights. Very few targeted studies have investigated the participation of self-advocates in human rights advocacy ([Birtha 2014a, 2014b](#)). It can be assumed that self-advocacy may have a rather complicated relationship with the human rights approach, especially because the above-discussed disability movement, since its start in the 1970s, has been concerned with and shaped human rights ([Harpur 2012](#); [Hurst 2003](#); [Pelka 2012](#); [Shakespeare 2013](#)). In fact, the human rights approach itself has grown out of the social model and disability studies ([Degener 2016](#); [Kayess and French 2008](#)), and as such it may have carried on with the heavy heritage of marginalising or excluding self-advocates.

The gradual development of rights-based legislation has long been an aim and tool for disability advocacy ([Degener 2000](#); [García-Iriarte et al. 2015](#); [Hurst 1999](#); [Vanhala 2010](#)), but not until the adoption of the Americans with Disabilities Act (ADA) ([Americans with Disabilities Act 1990](#)) did the human-rights-based language started to become dominant among disability advocates ([Quinn and Flynn 2012](#)). According to Theresia Degener, '*with the paradigm shift from the medical to the social model of disability, disability has been reclassified as a human rights issue*', where the ADA was a '*major milestone*' on the road toward equality ([Degener 2000](#)). From the 1990s on, similarly important national laws were adopted in almost all countries in Europe ([Vanhala 2015](#)), including Britain ([Disability Discrimination Act 1995](#)) and Hungary ([Hungarian Parliament 1998](#)).

The prominence of the human rights approach to disability advocacy was further strengthened by the CRPD. Ever since its ratification, the CRPD has been described by using enthusiastic and sometimes metaphoric language in academic literature: '*out of darkness, into light*' ([Kayess and French 2008](#)); '*new era or false dawn?*' ([Lawson 2006](#)); a '*moral compass for change*' ([Quinn 2009](#)); and '*a conscience for the global community on disability issues*' ([García-Iriarte et al. 2015](#)). The CRPD is most commonly mentioned among legal scholars as a '*new paradigm*' or '*paradigm shift*' ([Bartlett 2012](#); [Harpur 2010, 2012](#); [Kayess and French 2008](#); [Mittler 2016](#); [Sabatello and Schulze 2014](#)) which brings about the '*human rights model*' to disability ([Degener 2014, 2016](#)).

Such enthusiasm about human rights, however, is not shared by everyone. Prominent founders of the social model and disability studies ([Oliver and Barnes 2012](#)) have repeatedly asserted that contemporary human rights mechanisms are partial and ideological, and they fail disabled people because human rights laws are unable to challenge existing structures of power, leaving



fundamental socio-economic systems unchallenged. For example, British anti-discrimination laws will never be effective alone, without trying to achieve more profound politico-economic changes (Barnes and Oliver 1995). For others, for example feminist disability scholar Kristjana Kristiansen, the impact of disability human rights approaches is limited because *'the rhetoric is lovely ( . . . ) but there is no teeth in it'* (Kristiansen 2012). Others warn that cross-national DPOs and donor organisations using the human rights framework may ignore local DPOs' needs, their organisational knowledge and specific circumstances, and potentially co-opt them by providing funds for narrowly-understood human rights advocacy instead of acknowledging other issues such as local material needs in the Global South (Meyers 2016). Furthermore, critical disability scholars have raised concerns about global human rights as a potential form of colonisation that may maintain power imbalances between Western and non-Western interpretations of what disability rights actually mean for disabled people living in the Global South (Meekosha and Soldatic 2011). Notably, critics of the human rights approach rarely make reference to the specific needs and perspectives of self-advocates with intellectual disabilities or autism.

Although these concerns are still debated by scholars and advocates, nonetheless the CRPD—paraphrasing Hasler's observation about the role of the social model in the disability movement (Hasler 1993)—has become the new *'big idea'* of the international disability movement. Unfortunately, in the absence of focussed research it is unclear whether self-advocates are similarly enthusiastic and how they see the role of the CRPD and human rights laws in their own everyday advocacy. Although the CRPD itself makes it mandatory in Article 4 and Article 33 to include disabled people in the monitoring and implementation of the CRPD, it remains unknown how self-advocates with an intellectual disability or autistic self-advocates perceive their own involvement in the work of DPOs representing them. This paper explores these questions, through reporting the analysis of an empirical study on self-advocacy.

### 3. Methodology

The findings to be presented are part of a broader research project focussing on the participation of self-advocates within the disability movement. The project is a doctoral study that is based on empirical data from two countries, the United Kingdom (UK) and Hungary. Both countries have ratified not only the CRPD (Hungary in 2007, the UK in 2009), and other major UN Conventions such as the Convention on the Rights of the Child (both in 1991) or the Convention on the Elimination of All Forms of Discrimination against Women (Hungary in 1980, the UK in 1986), but both countries have several domestic human rights laws covering disability rights as well (Vanhala 2015). Furthermore, both Hungary and the United Kingdom have seen a number of national and local DPOs working for disabled people and using the human rights model—including dozens of civil society organisations in both countries that represent people with intellectual disabilities or autistic people.

The main objective of the doctoral study is to explore how people with intellectual disabilities or autism participate in the broader disability movement; in particular, how autistic self-advocates or self-advocates with an intellectual disability perceive their own advocacy work against the backdrop of contemporary disability advocacy. The main research question of the doctoral study is *'to what extent do self-advocates with intellectual disabilities and autism currently shape the policies and actions of the disability movement?'*

Although data comes from two different countries, the study is not a comparative one. Instead, empirical data is collected and analysed together from the two countries—it is expected that similarities between the two countries will suggest an increased level of validity of findings that may imply broader, international trends or tendencies. However, any differences between the two countries will be highlighted and explored.

The present study employs a qualitative methodology and forms the first phase of the doctoral research project. The main aim of this first phase was to conceptualise self-advocacy based on the perception of members of the advocacy movement of people with intellectual disabilities and autistic

people. Focus groups and semi-structured interviews were conducted in both countries. Themes for the data collection emerged from a comprehensive literature review. (The full list of themes discussed at interviews and focus groups is in Annex 1.) Recruitment started through major DPOs and the researcher's professional network, and later several participants were included through 'snowballing' sampling.

Understanding the present strengths and difficulties of self-advocacy would be difficult without appraising the overall situation of the autistic or intellectual disability movement, which includes not only strictly-understood self-advocates and their groups, but also previously mentioned forms of advocacy bodies such as parents' organisations, professional advocacy organisations or bodies, human rights watchdogs, or organisations of mixed profile (e.g., led jointly by disabled people and others). Therefore, the study takes an open approach to assessing the place of self-advocacy in the disability movement: both self-advocates and their non-disabled colleagues, supporters, allies and other advocates working in the field were asked to participate, thereby establishing an assemblage of various individual views on contemporary self-advocacy. The main inclusion criteria was that participants had significant experience in advocacy or self-advocacy.

Altogether 43 people participated in four focus groups and 25 interviews. Both individual interviews and focus groups (four in each country) were planned, but only in the (much smaller) United Kingdom were they organised where participants could more easily travel to focus groups. In Hungary, in order to provide wider geographical coverage, interviews were preferred because participants lived at various locations often several hundred kilometres apart from each other. In other cases, participants who lived close to each other preferred individual interviews for confidentiality or other reasons (e.g., limited time to attend focus groups or feeling anxious about talking in front of others). This limitation of the data collection, however, has minimal impact on how findings can be analysed and interpreted. Participants (Table 1.) were recruited from four sometimes overlapping types of disability advocates:

- autistic self-advocates ( $n = 11$ );
- self-advocates with intellectual disabilities ( $n = 8$ );
- family members and professionals with significant experience in advocating for/with autistic people: 'advocates in autism' ( $n = 10$ );
- family members and professionals with significant experience in advocating for/with people with intellectual disabilities: 'advocates in intellectual disabilities' ( $n = 14$ ).

**Table 1.** Participants.

Participants	United Kingdom	Hungary	Total
<b>Self-advocates with intellectual disability</b>	4 interviews (including 1 group interview, $n = 2$ )	1 focus group ( $n = 3$ ) + 1 interview = 4 participants	8
<b>Autistic self-advocates</b>	5 interviews	1 focus group ( $n = 4$ ) + 2 interviews = 6 participants	11
<b>Advocates working in intellectual disability</b>	5 interviews	1 focus group ( $n = 5$ ) + 4 interviews = 9 participants	14
<b>Advocates for autistic people</b>	5 interviews	1 focus group ( $n = 4$ ) + 1 interview = 5 participants	10
<b>Total</b>	Total in the UK: $n = 19$ participants	Total in Hungary: $n = 24$ participants	<b><math>n = 43</math> participants</b>

This open approach to recruiting participants was further expanded by not restricting participation to those who worked within formally established DPOs, because the disability movement consists of not only self-defined DPOs but also of other formal or informal groups of people and even individuals

who speak up against injustice or human rights offenses. Therefore, people belonging to grassroots groups and individual self-advocates/advocates were also invited to participate. This resulted in the inclusion of participants, who—for example—used to be involved in DPOs but at the time of data collection did much of their advocacy as part of informal or ad-hoc groups. Others, such as some self-advocates, had official membership in DPOs but they considered themselves ‘individual self-advocates’ and indeed did the bulk of their advocacy as private individuals. Others had extensive, sometimes decades-long experience in doing or supporting self-advocacy, but they also worked as ‘solo’ advocates, for example by running their own website, blog, publishing articles in local papers or books, giving trainings on several issues, etc. Some participants used arts as part of their self-advocacy work, working away from formal advocacy organisations. Attention was also given to other factors such as the size of the advocacy organisation or geographic coverage. In both countries, participants who are actively involved with the best-known umbrella DPOs participated as well as others who belong to local, grassroots groups, often working in remote, rural areas.

It was hoped that this open and inclusive approach to recruitment would provide richer data that demonstrates the opinions of many layers and groups of the social movement of disabled people.

The four categories of participants also overlapped, because some self-advocates ( $n = 2$ ) had both intellectual disability and autism; while some parent-advocates or professionals were active both in intellectual disability and autistic advocacy ( $n = 7$ ). There were parent-advocates and self-advocates who disclosed having other types of disabilities such as visual or physical impairments. Finally, it appeared during data collection that many so-called ‘professional advocates’ (such as trained advocates or support workers, DPO officials or human rights lawyers) had family backgrounds that included siblings or other family members with a disability. This implies that a significant part of the movement of intellectual disabilities or autism have a stronger, even lifetime commitment to advocacy that should be seen more than just a job they are holding.

The data collection was conducted in Hungary in late 2016 and in the United Kingdom in the first half of 2017. Interviews and focus groups were conducted in Hungary and in the United Kingdom. Participation was voluntary and anonymous. There were limitations to anonymity and confidentiality for focus groups where participants could mutually identify each other and hear each other’s opinions—consent forms highlighted this limitation and explicitly asked for consent from all participants. Similarly, consent was asked from all participant self-advocates when one support worker was present at a focus group with self-advocates. Reasonable adjustments were given to participants, for example focus groups and interviews were organised at venues with low sensory stimuli. Some participants asked to be interviewed on Skype to reduce anxiety arising from personal meeting. In other cases, the researcher consulted support workers to understand the communicational needs of self-advocates with intellectual disabilities. All information sheets, consent forms and complaint forms were produced both in Hungarian and in English, and also in easy-read Hungarian and easy-read English. Transcription of recorded interviews and focus groups was done by the researcher. All translations during data collection and data analysis were done by the researcher himself. The data collection was approved by the University of Kent Tizard Ethics Committee in June 2016.

For the analysis of data, thematic analysis was employed, using the NVIVO software. Interviews and focus group transcriptions were read several times by the researcher, which was followed by coding and identifying emerging themes. Questions or statements around human rights and the human rights advocacy of DPOs were included in the present analysis. All interviews and focus groups included the following themes/questions:

- How much do you know about the CRPD or human rights? How much do others know about them?
- What do you think about human rights and the CRPD in the context of your advocacy work or in general? Are they useful or effective tools?



- Please evaluate the involvement of self-advocates within DPOs or the broader movement of people with intellectual disabilities/autism by using the ‘ladder of participation’ by Arnstein (Arnstein 1969).

In the present article only those findings will be presented that closely relate to the topic of discussion: human rights and self-advocacy, and the participation of self-advocates in the work of DPOs and the disability movement.

#### 4. Results

Findings are organised under three themes that are central not only for self-advocates but for the whole of disability advocacy: *knowledge (of human rights laws)*, *usefulness (of human rights tools)* and *participation (in DPOs)*. These three descriptive themes derive from the interview/focus group guides where separate questions addressed participants’ knowledge of human rights, the perceived usefulness of human rights and self-advocates’ involvement in DPOs. All three themes have also been seen as essential parts of advocacy. Knowledge has been the focus of disability studies from its beginnings (Thomas 2002). Human rights tools should be an integral part of disability advocacy and their increased use is suggested by several authors (Flynn 2013; García-Iriarte et al. 2015). Participation has long been a core demand of disabled people since the early days of disability advocacy, when a British DPO laid down the foundations of the social model (UPIAS 1975).

Although it is acknowledged that international human rights treaties of the United Nations like the CRPD, and national legislation (including laws prior to or after the countries’ ratification of the CRPD) are distinct categories, and should be separated when discussing human rights, during data collection a simplified approach was taken. During interviews and focus group, both the CRPD and domestic laws such as the Equality Act in the UK (2010) and the Equal Opportunities Act in Hungary country (1998) were referred to as ‘human rights laws’ or ‘human rights legislation’, because most participants were assumed to have limited legal knowledge and to not necessarily be familiar with terms like ‘treaty’ or ‘convention’. This approach ensured that participants could not only understand questions or prompts about legal issues but that they also felt competent enough to speak confidently. Therefore, while acknowledging the vagueness of the wording, in the discussion of findings both the CRPD and national legislation will often be referred to by participants as ‘laws’.

##### 4.1. ‘I Am Only Aware in a Very Vague Way’—Knowledge of Human Rights

It has been widely acknowledged since the early days of the disability movement that knowledge is necessary for the empowerment of disabled people (Goodley 2011; Hasler 1993; Oliver 1990; Shakespeare 2013). ‘*Knowledge is power*’ the saying goes and indeed, understanding human rights in general or actual laws such as the CRPD seems to be a necessary element of human rights based advocacy.

All participants were asked questions about both their knowledge about human rights in general and more specifically, about their knowledge about the CRPD or domestic human rights laws. Usually in one single prompt was given such as ‘*How much do you know about human rights? Or actual human rights laws like the UN CRPD? Have you heard of these?*’ but when needed, further questions were asked or clarification was given, for example when people could not recall what the CRPD was. All participants agreed that knowing about and understanding rights was fundamental in order to seek justice or to do advocacy. Even those acknowledged the importance of laws who claimed they were not familiar with legal matters, for example because their advocacy work rarely covered legal issues. The overall approval of the salience of the law and rights is demonstrated by the statements of two British self-advocates with intellectual disabilities who make a clear connection between laws and their everyday lives.

Researcher: Do you think it helps if people with a learning disability learn about the law or rights?

Self-advocate 1 & 2: Yes!

Self-advocate 1: Yes, 'cause how they're gonna now what they are entitled to? Like all this disability living allowance! This is what's changing, isn't it?

At the same time, recognising the importance of law did not mean participants claimed actual knowledge about human rights. When asked about their familiarity with the CRPD or other human rights laws, an overwhelming majority of participants stated to have limited or superficial knowledge. A group of experienced parent-advocates, leaders of local and national DPOs in Hungary said:

Researcher: Are you familiar with human rights laws like the CRPD?

Advocate 1: I couldn't list up what it says, but I know about the CRPD.

Advocate 2: I wouldn't know either.

Advocate 3: I wouldn't know the whole thing but the parts about democracy I am familiar with, of course.

Advocate 1: I am not, for sure.

According to the leader of another advocacy organisation representing people with severe intellectual disabilities in Hungary: *'The families in our organisation don't have a clue about these, the Convention and all ...'*, and another professional advocate who has worked many years at a Hungarian national learning disability organisation adds *'I assume most people are not really familiar [with human rights]. And I am saying this because there haven't been studies or surveys to show how much people know about these things. Studies should be done!'*

Participants from the United Kingdom have similar claims, most of them reporting very little knowledge about human rights laws and some of them seeing very little awareness across the field of intellectual disabilities or autism.

I am only aware in a very vague way. I do know a little bit about the Disability Discrimination Act in this country which actually doesn't have many teeth when it comes to education. But I am not, I would not say I am very knowledgeable about these, not more than anyone else. (UK advocate in intellectual disabilities)

Yes, I have heard of it [the CRPD]. I can't say I'll tell you details of it off the top of my head right now. (laughs nervously) (UK advocate for autistic people and their families)

I have read things about it but can't remember the details. (UK advocate for autistic people)

Others recognise that knowledge about human rights or the CRPD itself is growing, but they see limited effects in the broader society or even among disabled people—and human rights may be associated with international DPOs like Autism Europe.

[The knowledge] is growing but that's just a very... ( ... ) You know, we live in a little bubble where we know these things and we talk about these things and get excited about these things but people next door to me never heard of them. And the majority of people with disabilities never heard of them. (UK advocate in intellectual disabilities)

I just don't [know much about them]... There was this Autism Europe thing, a written document about something... And then there's a European Convention on disability rights I think. And another one, it's again I think it's a worldwide one, that is part of English law. (UK advocate for autistic people)

The tension between the recognition of the importance of rights and the lack of familiarity with them was explained by several participants. Training may be helpful but it has limited effect in practice—for others membership in formal advocacy organisations, especially ‘big DPOs’ seems a decisive factor. The translation of rights on paper into actual advocacy actions may also be challenging.

Our organisation just got a bit of funding to start trainings on it [the CRPD]. It’s complicated. (. . .) You go to a training session where you hear you have the right to this and this and this, and what society and the state should be doing, and they don’t tell you what to do when it doesn’t happen. And I think that’s the big gap that people don’t know what to do when it isn’t happening.’ (UK advocate in intellectual disabilities)

Within our movement the problem is that even if we look at self-advocates, they are OK at the central organisation, and we have few groups here and there, if we include local self-advocacy groups . . . But even if we take local groups into account, they only cover very few people in a local town, if they even exist! Where are the others, what about them? (Hungarian advocate in intellectual disabilities)

The only people who are in touch with organisations would tend to know about it. (UK advocate in intellectual disabilities)

I don’t think they do [know about human rights]. They are thinking about their personal, one issue at the moment, or what they need. I think when what they need links directly that time with what’s in the news and then they link it altogether. But until that point I don’t think they really do unless they have someone or that’s their obsession. And then they would know about that, the processes. (UK advocate supporting autistic people)

Self-advocates themselves, similarly to their non-disabled colleagues, admitted often limited or even ‘*sketchy*’ knowledge about the CRPD and other human rights laws. For example, three Hungarian autistic self-advocates say:

Self-advocate 1: (whispering) I still have not read it!

Self-advocate 2: I have read it but I wouldn’t say I feel competent. Or in other words, I just don’t see where this Convention reaches my life or the lives of people I know, because I have never had to use it, to make a reference to it. Interestingly, whenever I have had to stand up for something it has never escalated that far, I never had to use them [human rights].

Self-advocate 3: I know it [the CRPD] superficially, and I come across it every now and then in my work. Last time about 2–3 weeks ago, I think.

Another Hungarian autistic self-advocate adds ‘*only those who are part of advocacy organisations would know about these things, and even then, this is a knowledge that takes years to be learned. And this applies not only to self-advocates, but parent advocates and professionals as well.*’ For two Britain-based self-advocates with intellectual disabilities the CRPD was completely unknown, even though they have been actively involved in empowering other self-advocates for years—on the other hand they claimed to have better knowledge of British human rights laws.

Researcher: Have you heard about the UNCRPD?

Both: No.

Researcher: And other human rights laws? The Equality Act? The Disability Discrimination Act?

Self-advocate 1: Yeah, we heard about all of these, ‘cause we used to go through all of them during the trainings.

Another participant reported having better knowledge of some domestic human rights laws.

Our kind of domain is so much about the UK and England specifically that it [the CRPD] just doesn't come up on the radar. (UK advocate for people with intellectual disabilities)

Some others see gradual improvements in the knowledge about the CRPD and other human rights instruments. An autistic self-advocate from Hungary stated *'Fortunately, more and more people hear about the Convention. The 'nothing about us without us' slogan could even be the best PR for it because it just puts it so clearly what it's all about!'*

Good examples were also mentioned. Self-advocates with intellectual disabilities who worked for umbrella DPOs in both countries were reporting having a deeper understanding of the CRPD and they themselves participate in producing materials about it: one of them gave an interview to a website run by self-advocates, another one wrote an article for their newsletter about provisions of the CRPD. However, this was a minority among participants.

Knowledge about human rights and their actual use in advocacy may be gained because people recognise their relevance. One participant from an advocacy organisation in Hungary fighting for people with severe intellectual disabilities stated: *'I would not know about them either if I didn't know that communication is a basic right which should be implemented across the education system so they should provide tools to support'*.

It is also important that several participants claimed to have no competence on human rights because rights and the law are seen as requiring special expertise or technical language. According to one self-advocate with intellectual disability in Hungary who is actively involved in CRPD-based advocacy: *'it is lawyers who know best. The CRPD is up to the lawyers, they are the ones who can comment on it!'* Such statements may expose fundamental problems in the empowerment of self-advocates in the human rights movement; if special expertise or highly educated 'experts' are needed to even talk about human rights then emancipatory knowledge may remain inaccessible to those who most need it.

#### 4.2. 'More Honoured in the Breach Than in the Observance'—Usefulness of Human Rights

Participants were also asked how useful they thought human rights laws such as the CRPD or national human rights legislation were. Since the disability movement has long engaged with legislative changes and all participants had substantial experience in advocating for themselves or others, it was assumed that participants would have enough knowledge to assess the effectiveness or usefulness of human rights in their own advocacy (or in the advocacy of others).

Many participants expressed that they do not use human rights law in their everyday advocacy, for example, because other laws are more relevant to their work. In this context, little acknowledgement was given to the fact that international or national human rights legislation itself can influence other laws. For example, some participants see the CRPD as too general to be used for specific cases.

To be honest we don't use the CRPD because when we go to meet a school principal we use the Education Act, so we prefer laws that are more concrete!!! And not ones that are more... general. So all in all I don't think we use it. (Hungarian advocate for autistic people)

I am sure we stored it [the CRPD] somewhere in our minds and we even use it somehow, but if we used it every day then I would probably be able to tell you what for ... So obviously we don't use it. (Hungarian advocate for autistic people)

Another advocate said although they do not use the CRPD in their everyday actions, it still formed the basis when establishing their advocacy organisation—and the CRPD is still very relevant for changing national laws.

The CRPD was seen as a basis when we started this whole thing, how to build up our organisation ... We did think about human rights. But we don't refer to them in our everyday work. But I also think that for a national level advocacy, when the national DPO

fighters for us, then it is crucial that they refer to the CRPD, because when they negotiate with the Government then the CRPD is important. It is another issue how seriously the Government take it. (Hungarian advocate for autistic people)

Other participants, like an advocate for autistic people from Hungary stated the CRPD was a useful basis for a monitoring they asked to be carried out to assess a social service's compliance with human rights. In some cases, the CRPD is seen to be the main point of reference during the advocacy of a DPO.

They use the CRPD all the time in ÉFOÉSZ [the Hungarian national DPO in intellectual disabilities], and they can tell you about anything they do how it relates to provisions of the Convention. So they can tell anyone why it is important what they are doing. (Hungarian advocate for people with intellectual disabilities)

For an autistic self-advocate in Hungary the question about the usefulness of the CRPD prompts an emotional reaction.

'I just pulled an ugly face, I am saying this for the sake of the voice recording, because it is such a deep and instinctive reaction I am giving. No! I don't see it working. They are trying, trying to take human rights seriously at many places but it does not work! ( . . . ) the Convention has made an effect, yes a minimal one.'

Similarly, an autistic self-advocate from the United Kingdom sees laws ineffective in practice: *'The National Autistic Society ( . . . ) has been effective in the political sphere in getting the Autism Act approved. But this is, quite like in Hamlet . . . "more honoured in the breach than in the observance". It's just ignored! So ineffective laws! I think this is very interesting.'*

For another Hungarian autistic self-advocate, it is not the Convention to be blamed for its limited effect:

The Convention has made an impact already, not a big impact but some things have happened, for example people started to discuss what it means and the whole concept has reached a lot of people. But I also think we should not have too high expectations from the Convention itself—it is a good enough concept, but it is ultimately up to us what is implemented of it.

There was a wide consensus among participants that human rights laws make too little impact on practical aspects of people's lives, which makes it difficult to see progress in human rights implementation both in the UK and in Hungary.

In my role I am not seeing the Convention as helping individuals it's a very . . . ehm . . . it's a pretty thing to have but whether it has made a difference in people's lives, lived experiences, I don't think very much. (UK advocate for people with intellectual disabilities)

I think human rights feel like big, vague ideas at a distance that doesn't feel very applicable. (UK autistic self-advocate)

For self-advocates with intellectual disabilities in Hungary, the CRPD has potential, although its implementation remains wanting.

Self-advocate 1: The trouble is that in my experience the UN CRPD only exists on paper, implementation is still lacking. The whole society will need to come together to make it real what is written in it.

Self-advocate 2: The UN Convention is good because it is written down what countries need to do after ratification. I think Hungary will go to the UN in October 2017 to tell them what happened. I think things are in progress, it is a bit slow but it is going.



Self-advocate 3: It is happening with hiccups. If you use rights you can achieve more.

Another participant, a human rights defender of people with intellectual disabilities in Hungary puts the emphasis on both practical and conceptual uses of the CRPD: *'The point is that it [the CRPD] applies general human rights specifically for disabled people, so rights cover them like everyone else. ( . . . ) and this is crucial not only on the theoretical but on the practical level, because the more people will use it the more significance it gets.'*

Several participants said that the lack of progress is due to extra-legal factors, for example the reluctance of government bodies or the lack of translation of rights into actual actions or good practices.

I think the rights are already there but the institutions and bodies are reluctant to apply them. The implementation of laws is very meek and there are no sanctions if rights are breached. (Hungarian advocate for people with intellectual disabilities)

I often see in my practice that although legislative changes are made by the government, but in many cases the practice don't follow. For example in supported decision-making, there are no support networks, no practical experience, there are no trainings for parents, no trainings for judges and so on. So it is not only legal progress that needs to be done, because we already have better laws than before but they are not implemented! ( . . . ) A lot of changes have been made following international examples and I don't know whom to blame for this, but there are hardly any existing practices based on the Convention. What could be better against the medical model than the human rights model, yes—but we need methodology to do it! (Hungarian advocate for people with intellectual disabilities)

One autistic self-advocate in the UK noted that existing human rights discourses may exclude overall systemic problems such as economic power imbalances between the Global North and the rest of the world.

How can someone from like a poorer country receive services up to the same level as someone from a rich country, if we are not looking at economic power and debt repayment and these kind of conversations outside the bill of human rights? (UK autistic self-advocate)

Some participants would like to see profound changes in how we see disabled people in society and they emphasise that the success of the human rights approach relies on a number of other factors, outside the remit of the CRPD—and even disability as an inclusive category is contested by the autistic community, leaving the rights-based language problematic in this context.

I think all of these [human rights] approaches are valid and necessary, but it is not going far enough. We still not have the conversation to restructuring normative society and the principles within the law and how our system works and equally in the academic establishment. (UK autistic self-advocate)

I think it [human rights] is filtering down in the wider disability movement, but I think autism is different and has its own agenda compared to wider... I mean there is still quite an issue about whether we want to call an autistic person disabled at all and there are many opinions about that among autistic people. It is nowhere near as clear-cut as with other disabilities and if I have sensory issues ( . . . ) People talk about minorities and the rights of women and things and then they have the disabled as a broad category but what they mean by disabled is someone in a wheelchair, that is their idea of what disability is. (UK autistic self-advocate)

In both countries, national contexts are seen to be responsible for the lack of progress in the implementation of the CRPD.

Rights can only work if the rule of law is respected by the state. You need the separation of powers, mechanisms independent from the government etc. We don't really have those anymore in Hungary. This is a new political system we have now. ( . . . ) Human rights are totally alien here, they are very uncertain, the state is only disturbed by them. (Hungarian advocate for people with intellectual disabilities)

I think some countries are better than others and the UK has chosen to mostly ignore it so there are very little investment in raising awareness of the Convention or any of the [UN] Conventions ... the children's lobby have done better but look how, the CRC has been in existence... it's been more than 30 years now. So I think children's rights are better known, disabled people's rights are not. In the UK, I mean. (UK advocate in intellectual disabilities)

On the other hand, not only negative statements were made. Several participants assessed the CRPD and the human rights approach as useful in that it is already driving some changes—including changes on the legal or discursive level.

Basically everything from nothing is . . . should be around the Convention. ( . . . ) I think thanks to people who have lobbied the government, and also people with learning disabilities we've made improvements. But I feel it's just . . . . What needs to be more practical is getting all governments to do it ( . . . ), but I think things are getting better. (UK self-advocate with intellectual disabilities)

The Convention is certainly there in the work of our organisation, it is a basis. A compass. (Hungarian advocate for people with intellectual disabilities)

To some extent yes, there are cases when it [the Equality Act] helps. The principles are good. I mean there are people who are willing ... I think there are... When people know what reasonable adaptations to make. (UK advocate for autistic people)

Now that you ask, yes, we do use the Convention, like last week I think we sent a letter to a head teacher and we mentioned it in it. (Hungarian advocate for autistic children)

The CRPD as a framework appeared to be powerful for some participants, inducting new ways of thinking about progressive changes not only nationally but also internationally.

The CRPD has given us a framework for having conversations about what people should expect. And because it is a common framework, it can be used across countries and it explains what it is reasonable to expect of your life and of your country. And I think that's a very useful tool for advocacy. (UK advocate for people with intellectual disabilities)

The careful enthusiasm and scepticism among participants about the usefulness of the human rights approach is largely based on their own experiences, both as advocates and as disabled people (or their relatives). One statement by a Hungarian advocate seems to be emblematic when he likened the slow progress in human rights implementation to another emancipatory movement: *'I agree with others. But I am an optimist, because the suffragette movement started in the 1920s and Switzerland only gave voting rights to women in 1972. This is 52 years. I still hope it will take shorter time for us.'*

#### 4.3. Self-Advocacy within Disabled People's Organisations

Finally, participants were asked to assess the participation of self-advocates within the DPOs representing them or within the intellectual disability/autistic advocacy movement. This aspect of the study is based on the pivotal provision made in Article 4 and Article 33 of the CRPD which makes it mandatory for state parties to ensure the involvement of disabled people in the monitoring and implementation of the convention. Arguably, such provision should be available to all disabled people,

therefore it is important to see whether self-advocates with an intellectual disability or autistic people participate in DPO decisions meaningfully or not.

To assess the participation in DPOs, a well-known visualisation was used; Arnstein's ladder of participation (Arnstein 1969) is a widely referenced conceptualisation of citizen involvement in decision making. (See Annex X.) Using the ladder of participation in the disability context is not unknown, for example it has been used when looking at the involvement of autistic people in research (Pellicano et al. 2014) and was referenced when DPO involvement in the monitoring of the CRPD was studied (Birtha 2014b). The ladder of participation offered itself as a particularly useful tool in the study because of its accessibility and relative simplicity. Nonetheless, for participants with an intellectual disability, a more simplified version was used with only five steps on the ladder (as opposed to eight steps in the original concept).

All participants were asked to assess where self-advocates stand on the ladder within DPOs representing them or within the autistic movement or the movement of learning disability organisations. (Prompts depended on participants' backgrounds, for example their personal experiences in DPOs.) Many participants found it hard to generalise but with the exception of two participants all of them agreed to locate self-advocacy on the ladder. Several participants were unable to point at one actual step on the ladder, instead preferred to provide approximate locations, for example 'somewhere down here' or 'somewhere in tokenism'.

Findings were consistent across all subgroups and the two countries, and not different between intellectual disabilities and autism: self-advocates have a low to moderate level of participation in organisations representing them, away from 'citizen participation', mostly standing around informing, consultation and placation. The overwhelming majority of participants saw self-advocates being on levels of tokenism within organisations claiming to represent them.

Below placation . . . ( . . . ) I think generally we would be in the level of tokenism. We tend to be listening but we actually don't give enough options for them and the support to be truly the way it should. (UK advocate for autistic people)

Participation is always individual, how you actually involve them, it is a process, but I'd say the average person with a learning disability in advocacy is there in the middle, in tokenism at best. (Hungarian advocate for people with intellectual disabilities)

Autistics are down there in therapy in general population, and in advocacy organisations maybe on the level of being informed. (Hungarian autistic self-advocate)

One autistic self-advocate in Hungary pointed out that the disabled people's movement itself is yet to comply with the CRPD: '*. . . actually, there is the saying "nothing about us without us", which I think is in the Convention itself, and this means they [DPOs] have to involve us, so that we are there in the decisions taken about us. But this is not happening at all.*'

Some participants see possible explanations for the tokenistic involvement of self-advocates in charities.

I still think this would be within the degrees of tokenism but slightly up, in the middle of this (consultation). And it's interesting you mention charities, because I do think sometimes there's a hidden agenda to speak for these people rather than allow them to have a voice themselves. There are some great charities out there, but there's also a lot of . . . careerist out there, people who made a quite comfortable career with a relatively good income from speaking on behalf of them. (UK advocate for people with intellectual disabilities)

Several participants stated that the level of participation is variable over time. According to a Hungarian advocate for people with intellectual disabilities '*we are trying to bring it up to partnership level in our organisation, but it is just not working yet*'. In some cases, improvements may happen, but sometimes there is a setback in progress within organisations.

Mencap moved toward citizen control and pulled back to placation and I think has slipped now to consultation in how it works. In terms of the broader disability movement insofar as there's one, the problem is that intellectual disability just hasn't managed to get any purchase at all. (UK advocate for people with intellectual disabilities)

For some autistic self-advocates in both countries, the progress in participation is happening—although only sporadically and slowly.

We are only starting to reach the level of informing, if they listen to us at all. Although we see there are already some organisations where they take us seriously and don't just tell us 'you little stupid thing, what do you want?' (Hungarian autistic self-advocate)

I think in advocacy, for the most part they would be in the middle. At the level of informing. What we are aiming toward is partnership, ( . . . ) so there are isolated pockets where there are good practices where it is moving away from tokenism. (UK autistic self-advocate)

There were few participants who saw the participation of self-advocates in DPOs largely at the lowest level, around manipulation, with 'no power'. For instance, a British autistic self-advocate stated '*As I said I don't feel part of the community, and I struggle with the language of intervention but the main trope is still around, the behaviour analysis and . . . equally there's . . . At large the establishment still has its power, so we are there, down (no power).*'

A notable exception to the majority opinion is that—consistently between the two countries—there were several self-advocates with intellectual disabilities who saw themselves being on the level of citizen control. For example, two British self-advocates with intellectual disabilities stated:

Self-advocate 1: Now? Definitely now in the top! When I was in the [care] home, back then, more down here, halfway through, therapy and manipulation. I felt I weren't in control. And I was pushing them limits to get my control. Because I knew what I wanted and I KNEW what I wanted to do but it's like how do I say it unless I'm doing something wrong.

Self-advocate 2: I was down there in the past, NO POWER but now up to partnership and control. Jumped from manipulation and now I am in the green.

Similarly, a Hungarian self-advocate with intellectual disabilities claimed '*I think I am up here on citizen control, because I get the information I need and I have worked a lot to achieve this so I can also help others to achieve it.*' This finding reasserts previous studies: self-advocacy groups for people with intellectual disabilities can provide meaningful control for people over certain aspects of their lives, including in their advocacy work. This must be recognised along with the broader observation made by most participants about tokenism in the movement, especially because although profound changes in the involvement of self-advocates are yet to be seen, self-advocacy itself has the potential to change people's lives which is a potential strength to build on when pursuing progressive changes in DPOs.

## 5. Conclusions

Findings were consistent across the two countries and they indicate that a significant part of the advocacy movement working for autistic people or people with intellectual disabilities have little actual knowledge about the CRPD and other human rights laws. Although there are some self-advocates and other advocates who are more familiar with human rights, they are likely to be found around 'big DPOs' such as national umbrella organisations that work closer to international organisations. This is consistent with the findings of Meyers (2014), who found that human rights frameworks are mostly pursued by national or international DPOs and local or grassroots organisations often follow different agendas. People involved in advocacy or in self-advocacy often see little relevance of human rights laws in their everyday advocacy and it is difficult for them to translate human rights into practical things. Significantly, some advocates and self-advocates feel they are 'not competent' to talk about

human rights because of the level of expertise it requires, which implies that they feel disempowered when they are expected to use human rights as an advocacy tool.

Self-advocates and advocates in intellectual disabilities or autism usually saw very little progress in the implementation of the CRPD and thought human rights are vague concepts that are yet to become relevant to their lives. Participants who saw progress observed legal changes that are yet to make real impact and progress was seen to be very slow. Both the reluctance of state bodies and broader societal or political factors, outside the powers of the CRPD were blamed for the lack of progress. On the other hand, other participants appraised the important change the CRPD has brought about in the discursive level, allowing for new dialogue about what is needed for real change.

Both self-advocates and non-disabled advocates agree that the involvement of self-advocates in organisations, including major DPOs is tokenistic and stuck on the level of informing, formal consultation or placation. The low level of meaningful participation runs the risk that the disability movement, even when using the ‘human rights model’, pursues advocacy targets that are set by others such as parents and professionals and not by self-advocates themselves. Existing power relations within the movement are not seen to be changing, leaving professionals and parents in control. Some participants also see ‘pockets of’ good practices but few of them see real improvements in the meaningful participation of self-advocates within the movement.

Although the findings of the study do not represent the views of all self-advocates (and all their non-disabled allies) in the two countries, the consistency of findings between the two countries indicates a strong relevance to other countries and the international movement of disabled people. The disabled people’s movement has been using the human rights model to challenge the continuing social exclusion of disabled people, but such change cannot happen until people with intellectual disabilities and autistic people get full membership within the movement.

The disability rights movement has a duty to address and openly discuss the continuously limited participation of self-advocates in the movement and start planning and implementing progressive changes accordingly. Therefore, the findings of the present article will be shared with DPOs and self-advocates in both countries and internationally.

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