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Research Paper

Engaging adolescents with disabilities in research☆

L'implication des adolescents en situation de handicap dans les recherches participatives

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Abstract

Adolescence is a time of transition from childhood to adulthood, but the social implications of adolescence vary from culture to culture and between socioeconomic groups. The impact of having a disability on the transition from childhood to adulthood can be significant. There is a dearth of research into the needs of adolescents with disabilities in low- and middle-income countries. In particular, the voices of adolescents are largely excluded from the research and decision-making that concerns their lives. This paper reviews methods by which adolescents with disabilities can be engaged in research. The benefits and challenges of using these techniques are discussed, using an example of a recent study conducted with adolescents with disabilities in South India. The paper concludes with a discussion of the benefits, drawbacks and implications of using participatory research techniques with adolescents with disabilities.

Keywords: Adolescence; Disability; Participation; Research methods; Photography

Résumé

L'adolescence est une période de transition entre l'enfance et l'âge adulte, mais les implications sociales de l'adolescence varient sensiblement selon les cultures et les classes sociales. Le fait de présenter des déficiences fonctionnelles au cours de cette période de transition peut être lourd de conséquences. Or nous manquons d'études concernant les besoins des adolescents en situation de handicap dans les pays à revenu

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faible ou moyen. En particulier, la parole des adolescents est encore largement exclue des recherches et des processus de décision concernant leur propre vie. Ce texte recense les méthodes qui permettent d'impliquer les adolescents en situation de handicap dans la démarche de recherche. L'article traite des avantages et des inconvénients des méthodes de recherche participative en s'appuyant sur l'exemple d'une étude menée récemment dans le sud de l'Inde avec des adolescents handicapés. Il se conclu par une discussion sur les bénéfices, les limites et les implications associés à l'utilisation de méthodes participatives avec des enfants en situation de handicap.

Mots clés : Adolescent ; Handicap ; Recherche participative ; Méthodes ; Photographie

Introduction

Adolescence is recognized as the period of transition between childhood and adulthood. The precise start- and end-points of this period are variably defined as beginning between the ages of 10 and 12 years and ending at or near 18 or 19 years (UNICEF, 2002a; Webster, 1961). The social implications of being an adolescent vary considerably from country to country, and even between groups of differing socioeconomic status within the same country. Adolescence takes varying and distinct forms both within and between different cultures (Brown and Larson, 2002). The majority of popular images of adolescence derive from a North American or European perspective. Adolescence does not exist as a unique social developmental phase in cultures where initiation into the workforce or marriage signifies entrance into adulthood from childhood. The presence of a disability in these cultures often leads to major negative consequences for adolescents. Exclusion from the workforce and little or no access to marriage and a family life implies a state of perpetual "childhood" and a denial of the rights and privileges afforded to an adult. The full extent of the implications of a disability on the life of an adolescent, particularly in low- and middle-income countries remains largely unknown.

According to estimates from the United Nations (UN), there are approximately 1.2 billion adolescents and youth (from 19 to 25 years of age) around the world, and of these, nearly 80% live in low- and middle-income countries (UNICEF, 2002a). How many of these adolescents have a disability? The oft-quoted global prevalence of disability is 10% in the total population of any given country. There is little evidence in the research literature to support this figure and recent data suggest that this number may be inaccurate and inflated. Prevalence figures are influenced by the method of data collection, the definition of disability in the country in which data are collected, and the implications of reporting a disability, among other factors (Loeb et al., 2008). Recent data suggest that the prevalence of disability is as low as 0.2% (Helander, 1993) and as high as 35% (United Nations, 2008). Using a conservative figure of 3% as the prevalence of disability, we estimate that there are approximately 36 million adolescents and youth around the world with a disability, with nearly 29 million of them living in low- and middle-income countries.

Young people with disabilities are marginalized throughout the world (UNICEF, 2005). This is particularly true in low- and middle-income countries, where there are great discrepancies in expectations of, and access to, services by different groups of people. Adolescents with disabilities are also affected by local taboos and beliefs about disability. The added factor of poverty experienced by some groups of adolescents with disabilities can further restrict their inclusion and participation. Adolescents with disabilities need to be included and should participate in

education, health and social life, and these needs are no different than those of their peers. Their access to such participation is often blocked.

> "*What distinguishes this large group of youth are not their common needs, but the fact that these needs continue to go so largely unmet*" (Groce, 2004).

More critically, these needs are largely unrecognized and unknown.

Little has been said about adolescents with disabilities in the literature on disability and rehabilitation. The majority of research with adolescents has been conducted in North America or Europe. A search of the current published literature revealed that there has been little to no research on adolescents with disabilities as a distinct group in low- and middle-income countries. Adolescents can only be provided with meaningful supports for inclusion and participation in all facets of society when they are engaged in research, policy planning and programme implementation concerning them and their lives. This paper will discuss the importance of engaging adolescents in research and the methods by which this can be achieved. The paper will review the benefits and drawbacks of using participatory techniques with adolescents with disabilities in low- and middle-income settings.

Background

Why engage adolescents? The reality and the rhetoric

Article 12 of the UN Convention on the Rights of the Child (UNCRC) (United Nations, 1989) states that participation is a right that should be afforded to all children: "*States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child*". Article 7 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) re-iterates the sentiments of Article 12 of the UNCRC, with the additional caveat that "*. . . children with disabilities [should] be provided with disability and age-appropriate assistance to realize that right*" (United Nations, 2006). In addition, Article 23 of the UNCRC states that children with disabilities "*should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community*" (United Nations, 1989). The right to full and equal participation is also detailed in Articles 29 and 30 of the UNCRPD.

Full and equal participation, as well as the right to express views and opinions, must extend to research and policy planning that involves children and adolescents. In a world where a significant power differential exists between adults and children, the opportunity to express themselves in research will provide adolescents with a sense of empowerment and a more complete sense of involvement in decision-making that directly affects their lives (Punch, 2002). This is particularly important for adolescents with disabilities, for whom decisions are often made by parents, caregivers, teachers and therapists, with little regard to their own desires, goals and expectations of life. The prevailing attitude of "adult knows best" is especially evident in programme planning and implementation for adolescents with disabilities.

Recommendations for research and programme development involving adolescents have started to recognize the importance of including them in the process. The Society for Adolescent Health (in the United States) published revised guidelines for research involving adolescents in 2003 and emphasized the need to conduct research "with" adolescents rather than "on" adolescents (Litt, 2003). Although these guidelines refer to adolescents in general, there is no explicit mention

of adolescents with disabilities. A review by the United Nations Children's Fund (UNICEF) indicated that programmes aimed at adolescents with disabilities which were deemed to be successful were those where young people were involved in planning, oversight and evaluation (Groce, 2004). A review of the environmental factors affecting participation of children with disabilities concluded that any research "*. . . must include discussions with children themselves and must focus on those aspects of attitudes, support, and relationships that are important to them*" (Mihaylov et al., 2004, p. 302).

It is important to distinguish between the increased participation of adolescents in research, and the implementation of participatory research with adolescents. The main difference between traditional research and participatory research is the designation of the key decision-maker. While an adolescent can be a participant in research by virtue of being a subject of research, this does not imply full involvement in all aspects of study design, evaluation, or implementation of findings. The researcher often maintains control over the final decisions regarding how the research data are analyzed, disseminated and put into practice. True participatory research would require the adolescent to have some level of input into design, data collection and analysis. Acquisition of self-determination skills is a prerequisite for successful transition from adolescence to adulthood. Self-determination is defined as the ability to take responsibility for making choices and decisions about life while being free from outside influences (Wehmeyer, 1992). The philosophy of self-determination was evaluated in reference to school transition programmes in Australia for students with disabilities (Laragy, 2004). Findings indicated that student participation in decision-making resulted in increased employment and participation in community activities.

While participatory research with adolescents with disabilities is the ideal, current research evidence suggests that simply participation of adolescents in research has yet to become common practice. The move from rhetoric to reality is particularly slow in occurring for adolescents with disabilities, whose inputs and voices are largely left out of research and decision-making concerning their lives. In an investigation into the perceptions of families of adolescents with cerebral palsy, the families and their children indicated that, above all, they "*asked to be listened to, they asked to be treated with respect and they asked for equitable access to information with less bureaucracy*" (Darrah et al., 2002, p. 548). Adolescents indicated frequent occurrences of being spoken about, rather than being spoken to, by health professionals and other service providers.

A review of the literature on adolescent participation in research revealed some positive changes. Although they did not include adolescents with disabilities, work carried out by UNICEF has demonstrated success when involving adolescents in designing and delivering services aimed at their peers (UNICEF, 2002b). Bent et al. (2001) conducted a study in which adolescents and young adults with disabilities were involved in determining the design of the study. This pilot study investigated the participation of young adults with physical disabilities and found that self-esteem and physical barriers were their biggest concerns. The unique feature of this study was that the participants were directly involved in determining the design of the study, not merely in the data collection process. In another study, the formal process of participatory action research (PAR), which will be discussed in more detail in the following section, was tested with adolescents with special needs as a way to help them deal with issues they faced in their daily lives (Burstein et al., 2005). Participants chose personal goals and were encouraged to formulate plans to achieve these goals, as well as documenting their progress. The researchers concluded that this was an effective process, even for adolescents with significant disabilities. Adolescents were seen to take more personal responsibility for their health. The process was deemed to be empowering, and "*help[ed] participants focus on solutions rather than personal frailties*" (Burstein et al., 2005, p. 200). Laragy (2004) indicates that employing the principle of self-determination leads to the

accomplishment of preferred outcomes, but she also questions "*. . . whether. . . society is prepared to give this the necessary priority and resources to make it happen*" (p. 528).

How can we engage adolescents and youth in research?

Recognizing the importance of increasing the participation of adolescents in research and policy planning, particularly adolescents with disabilities, is a partial step. We must now consider ways in which participation can be implemented and integrated into traditional scientific approaches. Some researchers maintain that research with children requires different skills and approaches as compared to research with adults. Although these views can be challenged, a few factors merit consideration. First, the power differential that exists between adults and adolescents will have an impact on the quality of the data that are gathered. The domination of adults in society and in decision-making concerning the lives of young people means that many adolescents are not accustomed to expressing their opinions or being treated as equals (Punch, 2002). This may be particularly true for adolescents with disabilities who frequently have decisions made on their behalf by parents, caregivers or other adult authority figures. The attitudes of adults towards children, and their assumptions about children's behaviour will influence research and data collection methods (Punch, 2002). Where adolescents with disabilities are concerned, it may be a case of misinformed assumptions about their ability to communicate their thoughts and feelings, and their ability, in general, to participate in research, planning and service delivery. Basic skills and techniques used in all research still apply to research with adolescents. Communication should be at an appropriate level, the tasks should be age-appropriate, and cultural and social factors should be considered. Researchers need to create opportunities where adolescents feel comfortable in speaking up and having their voices heard (O'Kane, 2000).

One of the first research methods to be used with disenfranchised groups was Participatory Rural Appraisal (PRA). This technique was first used with illiterate agricultural workers in an effort to facilitate the process whereby they took the necessary steps to change their lives (Cornwall and Jewkes, 1995). The technique has expanded to include similar methods such as PAR and Rapid Rural Appraisal (RRA), among others. The move towards participatory research highlights a recognition of the rights of the people about whom the research concerns, and provides them with a sense of ownership over the outcomes of the research (Cornwall and Jewkes, 1995). The shift towards participatory research involving adolescents, in particular, was predicted by Litt (2003) to meet extra resistance by virtue of the fact that it involved a group that was traditionally seen as unable to have a greater role in research.

Common research methods used in PRA/PAR are visual techniques such as mapping, drawing and photography. While formal PRA/PAR methods are less commonly used with children, visual methods are frequently used. Drawing has been used by a number of researchers: in rural Bolivia to study how children negotiate independence (Punch, 2002); to investigate how children understand and interpret illness (Guillemin, 2004); and to understand how street children in Uganda interact with their sociospatial environment (Young and Barrett, 2001b; Young and Barrett, 2001a). The creation of video recordings has been used with children to understand their interpretation of illness and their experiences of having severe asthma (Rich et al., 2000; Rich et al., 2006).

Another widely used visual research technique is photography. Photography is an established method of participatory research (Boyden and Ennew, 1997; Wang and Burris, 1997). Using this technique, participants are provided with cameras and asked to photograph images that are relevant to the research question or required for data collection. It has been used with youth in deprived neighbourhoods to explore quality of life issues (Morrow, 2001), and through photo

diaries with street children in Uganda (Young and Barrett, 2001a). Photography has also been used with children in rural Bolivia (Punch, 2002). Photography can be more effective than drawing as a research tool, although it is more resource-intensive. Adolescents, for example, may consider drawing to be a "childish" activity, and would prefer to engage in a photography task.

"Photovoice", developed by Wang and Burris (1997), is a methodological variant of photography as a visual technique of data collection. Photovoice is unique because "*. . . it gives cameras to people who might otherwise not have access to such a tool, so that they may record and catalyze change in their communities, rather than stand as passive subjects of other people's intentions and images*" (Wang and Burris, 1997, p. 370–371). Photovoice allows people to document specific concerns and provides them with the basis on which to engage in dialogue about these issues. It was also developed as a method to reach policy-makers in order to influence change at the community level. Photovoice has been used successfully with group of adolescents in an after-school youth centre (Strack et al., 2004).

There are many methods through which adolescents and youth can be engaged in research. The Commonwealth Secretariat (2005) has published a manual to provide guidance on increasing the participation of adolescents in programme planning and implementation. The key issue is that their involvement must not be tokenistic. They must have full and equal opportunities to contribute to all stages of planning, research, implementation and decision-making about services which impact their lives. Although there are several participatory research techniques that can be used with adolescents, none have been used with adolescents with disabilities in low- or middle-income countries.

Using photography with adolescents – an experience from the field

As outlined above, there are several participatory research techniques that can be employed with adolescents, including adolescents with disabilities. The benefits and challenges of using these techniques are discussed below, using an example of a recent study conducted with adolescents with disabilities in South India.

Methods employed

Photography was used as a data collection technique in a study of the perceptions of adolescents with disabilities about participation and inclusion in South India. The use of photography was intended to be a nondirective technique to facilitate focus group discussions. As underscored by Mihaylov et al. (2004), any research investigating participation of adolescents must include them in the discussion. This study did not employ a formal PRA/PAR approach. The research also did not adhere strictly to the original "Photovoice" concept as outlined by Wang and Burris (1997). It did, however, use concepts from both approaches as the basis for the study design.

As discussed earlier, drawing is frequently used with children to engage them in research and discussions about their lives. It was determined that drawing would not be an appropriate activity for adolescents. Punch (2002) iterates that drawing, as a technique to foster discussion, is ineffective when used with children who are too old and self-conscious about their perceived ability (or inability) to draw adequately. A manual task, such as drawing, also would not be appropriate for adolescents with physical disabilities who had impaired hand function. Other participatory techniques, such as drama, were also not considered due to the language barrier between the researcher and the participants.

Adolescents from two different urban slum communities and a special school for children with disabilities in the city of Bangalore, in South India, were invited to participate in the study. Adolescents were included if they had a physical impairment leading to a mobility limitation, and excluded if they had a severe learning disability. Participants with multiple physical and sensory impairments (vision or hearing) were also included. In total, 37 adolescents with physical impairments between the ages of 13 and 19 years participated in the study.

Each of the 37 adolescents was provided with a disposable camera. Instructions for correct use of the cameras were reviewed and participants were shown how to use the flash, how to forward the film in the camera and given some basic tips on effective photography. Participants were asked to take pictures which documented:

- things that made them happy/that they enjoyed;
- things that made them sad;
- things that made them angry or frustrated;
- things in their life that they wanted to change/make different.

The four topics were chosen to represent emotions rather than material objects. While it was necessary to provide some technical guidelines, excessive guidance about the types of pictures to take was not provided in order to maintain an open data collection process. The goal was to minimize researcher influence on the subject matter of the pictures. Rather, the aim was to allow the adolescents to express themselves freely in order to encourage an open discussion in subsequent stages of the study. Adolescents whose impairments prevented them from being able to use the camera independently were told that they could ask for assistance from a friend or family member, but that they should specify the content and subject of the photograph.

Adolescents were given one week to complete the task. After this period, cameras were collected by the researcher, the pictures were developed, and a follow-up focus group discussion was held with the participants. Adolescents were given an opportunity at this focus group to share their pictures with each other before the formal focus group discussions began. With consent from the adolescents, negatives were retained by the researcher for use in latter stages of the study, but all participants were given an album of their pictures to keep.

Benefits and challenges experienced in this study

Overall, the use of photography with the adolescents with disabilities was a successful method to facilitate open discussion. The participants were enthusiastic and keen to learn how to use the cameras properly. Adolescents also asked many questions to clarify the intent of the task. They were immediately protective of their cameras and were reluctant to let anyone else use them or even hold them. Of the 37 cameras which were distributed, only one camera was stolen. This was replaced immediately and the adolescent was able to complete the task. Three participants requested assistance from their mothers to use the cameras because of physical impairments. All three reported that their mother did not influence their choice of subject. The number of usable pictures taken by the adolescents varied from 6 to 18 pictures, of a total possible 27 exposures. Most importantly, many of the adolescents told the researcher that they were honoured to be trusted with the task and pleased to be given the responsibility of contributing to the research study.

Most participants, particularly those from lower socioeconomic backgrounds, had never used a camera, nor did they possess photographs of themselves or their families. The photography task

in this study allowed them to gain new experiences and skills. For the adolescents, the added benefit of being able to take and keep photographs of meaningful people and events in their lives was equally important. In spite of the doubts expressed by local partners, the adolescents were more than able to complete the task and contribute in a meaningful way to the research study.

The photography task was not only beneficial in increasing the participation of the adolescents with disabilities in the research process, but was also successful from a research perspective. The aim of using this technique was to allow for an open discussion amongst the adolescents about the facilitators and barriers to participation and to allow the researcher to engage with adolescents. Any apprehension or reluctance to speak on the part of the adolescents was quickly overcome during the time they spent sharing their pictures with each other. The adolescents were then asked to sort their pictures into thematic piles based on the four topics (happy/sad/angry/want to change). Once sorted, the researcher was then able to engage with the adolescents about the motivation and thought behind the pictures. Discussion of specific pictures quickly led to conversations about other pertinent issues in the lives of the adolescents with disabilities, which led naturally into discussions about participation and inclusion.

Although the method described above did have significant successes, there were some challenges with using photography with adolescents with disabilities in this setting. First, the local partners expressed clear misgivings that the method would be unsuccessful in providing meaningful information. Some repeatedly insisted that drawing should be used, rather than photography. As Punch (2002) states, it is more likely that drawing will be ineffective when used with older children. The physical impairments of some adolescents in the study would also have prevented them from participating in drawing tasks. It was challenging to reassure the local partners of the merits of the technique. The reluctance of the local partners and the doubts they raised about the feasibility of including adolescents in the data collection process were similar to those discussed by Punch (2002) and Litt (2003).

Second, the use of disposable cameras was not ideal. Disposable cameras work most effectively in brightly-lit conditions, particularly outdoors. Although the cameras all had a built-in flash, this was not particularly effective in poorly-lit conditions. The highest quality pictures were those taken outdoors or during the day. Many participants reported that they had taken more pictures than were printed. Some participants were disappointed that all their pictures were not developed, but most were pleased to see even a few photographs. Adolescents were keen to verbally describe the pictures that were not printed during the focus group discussions. Financial constraints prevented the researchers from using other types of cameras for the study. More reliable cameras would likely have resulted in more usable pictures from the participants.

Third, due to time constraints, participants were only able to take one set of photographs. It would have been interesting to repeat the exercise with themes derived from the initial focus group discussion. The timing of the exercise was also important. If the week during which participants were asked to take the photographs fell during a festival or holiday, they were unlikely to spend more than a day or two taking pictures. A minimum of a week is an ideal length of time for participants to have the cameras to ensure a wide variety of pictures. Providing participants with a longer time in which to complete the task may provide more in-depth information.

Finally, the photographs taken by the adolescents with disabilities did not always directly address the research question. Some participants were able to capture a wide variety of images that illustrated their thoughts about participation and inclusion. Others, however, focused more on taking pictures of themselves or their families. These participants often used the photographs of other participants as a catalyst for the expression of their own thoughts and feelings. Although most participants were thus able to engage in the focus group discussions, it was difficult to know

if they were expressing original thoughts. As described above, giving the participants more time to complete the task or carrying it out in several stages may allow for the expression of more original thought by more participants.

Discussion and conclusion

> "*The world will not solve its problems until it learns to do a better job of listening to what young people have to say and then collaborating with them to bring about needed change*" (UNICEF, 2002a).

The right of children and adolescents to have their voices heard and participate in decision-making processes is stipulated in the UNCRC, and again in the UNCRPD in reference to people with disabilities. Participatory research processes, then, are not just recommended, but an obligation of researchers in order to meet the basic rights of adolescents with disabilities. Further, active participation in decision-making is a key factor in self-determination, and has been shown by researchers to have important positive effects on the success of adolescents with disabilities in achieving desired goals (Laragy, 2004).

Ideally, PRA/PAR techniques that have previously been utilised with adults should be extended to adolescents. In doing so, participants would be involved in determining study questions, designing study methods, assisting with data collection, analysis and finally, dissemination of the results. Of all the literature reviewed in this paper, however, none implemented PRA/PAR in its purest form. Only one study involved adolescents in the process of study design as well as data collection (Bent et al., 2001). What the reviewed studies do illustrate, however, is that there are varied ways in which children and adolescents can be involved in the research process, and that they have the ability and interest in being active participants. Experiences from the fieldwork discussed in this paper show that adolescents with disabilities are capable of participating in the data collection process.

Photography is an effective method to facilitate discussion with adolescents. It provides adolescents with a means of age-appropriate expression. As the study in South India illustrates, adolescents with impaired fine motor skills were also able to engage in this process with the assistance of another person, while continuing to maintain control over the final product. Adolescents with disabilities around the world have long been the recipients of programmes designed for them by adults. Often, these programmes are based on the needs of younger children. This is particularly true in low- and middle-income settings, where the focus of many rehabilitation programmes are on the needs of parents or young children. Involving adolescents with disabilities in the research process by providing them with a means of expression, such as photography, is the first step in ensuring that their voices are heard.

The implementation of participatory research processes is not without its constraints and challenges. In addition to the challenges encountered in the study described above, there are other constraints of using photography with adolescents. The influence of family members and friends is unknown. In the study in South India, the adolescents were encouraged not to let other people use their cameras. Empirically, it appeared that the majority of the adolescents were solely responsible for their pictures. It is difficult, however, to know the extent to which family members and friends influenced the choice of pictures taken. Carrying out the photography task over a longer period of time where adolescents would be able to take several sets of pictures may allow for a more accurate representation of their views.

The extension of participatory research processes, such as PRA/PAR, to adolescents with disabilities has been viewed by some as being too time-consuming or difficult. However, not including the perspective of adolescents with disabilities in research for these reasons suggests that their views are unimportant (Garth and Aroni, 2003). The study from South India demonstrates that it is possible to ask adolescents with disabilities to take on a more active role in the research process. It is important to note, however, that this group did not include adolescents with severe communication or learning disabilities. This is a group that remains excluded from participatory research processes for the specific reason that including them is challenging and more resource-intensive. A review of research with children and adolescents with more severe impairments shows that they value participation and demand more involvement (Cavet and Sloper, 2004). In keeping with the UNCRC and the UNCRPD, however, these adolescents must be provided with adequate forms of communication to facilitate the expression of their views (Cavet and Sloper, 2004). Visual techniques, such as photography, are alternate forms of communication that should be further explored with adolescents with significant motor and sensory impairments.

It is incumbent on researchers interested in the lives of adolescents with disabilities to extend their involvement and participation in the research process. It is well recognised that adolescents with disabilities are capable of expressing their views, and have meaningful information to provide. The challenge to researchers now is to ensure adolescents are involved in the design of research studies and the analysis and dissemination of results. Only then can programmes and services be aimed directly at meeting their specific needs and allow them to fulfil their potential as they make the transition to adulthood. Successful inclusion and participation in adolescence leads to success when assuming adult roles and responsibilities. The voices of adolescents with disabilities have been silent for too long. We must engage them and allow them to tell us how we can better facilitate their future successes.

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