Seeking and establishing the views of disabled children and young people: A literature review

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Listening to children's voices and accessing their views about service provision in the education, health, social services and legal disciplines has received increasing international and national focus (Lewis, 2004). Establishing the views and consent of children and young people is a fundamental aspect of child protection social work whereby children's safety relies on their being listened to and involved in decisions about their own lives (Franklin & Sloper, 2007). Much legislation around the world now emphasises the importance of seeking and utilising children and young people's opinions (Morris, 2002). New Zealand has legislative, policy and practice requirements to this effect, as well as obligations through international and local instruments such as the United Nations Convention on the Rights of the Child (UNCROC) and the New Zealand Disability Strategy.

Despite these requirements and obligations, international and local research has demonstrated that disabled children have been largely excluded from consultation and involvement in decisions that affect them (Rabiee, Sloper, & Beresford, 2005). In particular, social workers' communication with disabled children and young people has been identified as problematic, as social workers often assume some disabled children or young people cannot communicate as a result of their impairment (Kelly, 2005).

This article reviews the literature since 2000 on communication and participation with disabled children and young people within the context of current disability theory. Based on the literature, a set of practice tips regarding facilitating participation and communication with disabled children and young people is included at the end of this article.

Findings

Communication and participation?

Communication and participation are necessary to seek and establish the views of a person with whom we are working.

Communication occurs in a variety of ways, but in essence "is a social process, in which a sense of meaning, a rapport or understanding, and a relationship develop between people who are communicating with each other" (Westcott & Cross, 1996, p. 83). Language, including verbal, written, or pictorial, is one way of communicating. Other non-verbal methods include tone of voice, body language, facial expressions and laughing and crying (Morris, 2002). By comparison, the term participation is a multi-layered concept that can mean taking part, being present, being consulted or a transfer of power where the participant's views have influence on decisions (Franklin & Sloper, 2007). "Genuine participation is based on informed consent and requires that children and young people are given full and accessible information about the decisions to be made and/or the participation activity" (Franklin & Sloper, 2007, p. 9). Franklin and Sloper (2007) believe there are different levels of participation and for some children with cognitive impairments it must be seen as valid for participation to include choosing between two different options.

"Fundamental to achieving the overall aim of participation is therefore to develop communication methods, which can maximise children's communication potential to express themselves and address the barriers they face. The other key component for effective participation is to recognise the fact that communication is a two way process requiring others to learn and understand how a child expresses herself/himself." (Rabiee et al, 2005, p. 386)

Children's participation has become an important consideration within legislation

Up until the late 20th century, children were regarded as part of their parents' property and had few or no rights (Rowse, 2007). However, a recent international shift has recognised children's ability and right to participate, express views and make decisions about their own lives, including children who were previously seen as unable to form a valid view, for example disabled children (Ware, 2004). This shift is likely to have been influenced by the deinstitutionalisation, independent living and consumer advocacy movements (Strock-Lynskey & Keller, 2007). Policy, practice and research have begun to reflect this change (Ware, 2004), particularly in the United Kingdom where children's participation in decision-making has become common within children's service sector legislation (Lewis, 2004).

The UNCROC has been important in raising the political profile of children's rights (Mortimer, 2004) and holding governments to account for recognising and meeting children's needs (Rowse, 2007; Willow, 2002).

Underlying UNCROC is an assumption that being heard as service users is a reasonable goal for all children and that barriers can be overcome (Lewis, Newton & Vials, 2008).

Despite a dearth of New Zealand literature, Kelly (2003, 2005) highlights the importance of the New Zealand Disability Strategy, which she believes

uniquely recognises the needs and rights of disabled children.

Underpinning theoretical perspectives

The social model of disability was the dominant theoretical framework evidenced in the literature. As an effective and empowering way of working with disabled children and their families (Griffiths, 2002; Wilson, 2004), this model has become widely accepted and promoted across the world and in New Zealand (Kelly, 2005).

The social model of disability argues that "the experience of disability is essentially a reflection of the existence of social obstacles and that if society were organised differently ... many people would be able to manage their lives quite successfully without experiencing constant frustration and discrimination" (Connolly & Ward 2008, p. 97). Therefore, while impairment is part of the individual, he or she is further disabled by social and attitudinal barriers (Wilson, 2004).

By contrast, the traditional medical or individual model of disability "locates the 'problem' of disability within the individual and : sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability" (Oliver, 1996, p. 32). Social work practice based on this model is oppressive (Griffiths, 2002). It promotes deficit-based thinking about disability and impairment whereby children are defined by what they cannot do, rather than what they can (Rabiee et al, 2005). This can lead to exclusion, as Kelly (2003) found with some social workers who excluded disabled children from review meetings because they assumed they either could not participate or they would be disruptive. Griffiths (2002) and Wilson (2004) suggest the social model of disability is more effective and empowering because children and young people can be assisted to identify and overcome the personal and social barriers they face.

Several authors also framed their discussion within a human rights discourse (Buchanan & Gunn, 2007; Burke & Cigno, 2000; Morris, 2001; Watson, Abbott, & Townsley, 2007), asserting

that failing to ascertain the views of disabled children or ensure their participation in decisions affecting them was a denial of their fundamental human rights.

Disabled children are less likely to have their views established

Despite moves to ensure children and young people are involved in decisions about their welfare, the literature shows that disabled children continue to be less likely than other groups of children to participate (Preece, 2002; Stalker & Connors, 2003), have their voice heard (Wilson, 2004) and as a result they have been largely excluded from consultations and involvement in decisions affecting them (Rabiee et al, 2005).

Stalker and Connors (2003) suggest many social workers avoid seeking children's views because they assume they are "too young" or "too disabled" to express them, and they put little effort into finding alternative methods of communication. As Rowse (2007, p. 74) states, "for a disabled child it is less likely that their views will be sought".

Participation and consultation tend to occur more commonly with those who present fewer challenges to the process, such as those with physical and/or sensory impairments (Preece, 2002). Researchers found that the voices of those with profound and complex learning difficulties (Whitehurst, 2006), intellectually disabled children (Kelly, 2003), and those with a communication and/or cognitive impairment (Morris, 2001, 2003; Rabiee et al, 2005) remain largely silent.

A child or young person's age also influences whether or not consultation occurs. Franklin and Sloper (2007, p. 118) identified that "participation at any level is only a reality for a small number of disabled children and young people, and that the majority of those who are participating are from the older age range". Preece (2002) and Mortimer (2004) similarly found studies more commonly focus on teenagers than on younger children.

The field of social work has been criticised for the lack of consultation with disabled children. Social

workers generally feel they lack the necessary skills or experience to communicate with this client group (Buchanan & Gunn, 2007; Griffiths, 2002; Kelly, 2005). "It is acknowledged that the pressures on social workers are great, but lack of time or the excuse that it is too difficult are not good enough reasons for not consulting with disabled children" (Griffiths, 2002, pp. 10–11).

The literature suggests that the growth of participation of disabled children appears to be slower than that of non-disabled children and that further emphasis is needed to develop ways of listening to all disabled children (Franklin & Sloper, 2006; Monteith & Cousins, 2000).

Disabled children can express views

The literature demonstrated that communication and participation with disabled children and young people can elicit valuable insight across a variety of subjects.¹

Many of these studies described how children's views were obtained, and advocated for including children and young people in designing the research, for example Kelly's (2003) research encouraged children to decide how the research visit would proceed and what activities they would engage in.

The children and young people involved in these studies also had a range of impairments demonstrating that participation was possible with a vast array of different impairment types, including for example communication and cognitive impairments, autism spectrum disorder, multi-sensory impairment, complex health care/ medical needs, learning impairments, intellectual impairments and those with high levels of support needs (Morris, 2001).

¹ For instance sexual abuse (Oosterhoorn & Kendrick, 2001), recreational activities (Davis & Watson, 2002), schooling and educational experiences (Davis & Watson, 2002; Lewis, Newton & Vials, 2008; Wilson, 2004), educational and transition planning (Taylor, 2007), outcomes of social care and support services (Rabiee, Sloper & Beresford, 2005), family-support services (Kelly, 2003, 2005), multi-agency services (Watson, Abbott & Townsley, 2007), social service provision (Buchanan & Gunn, 2007), medical treatment (Rowse, 2007), short-term residential care (Preece, 2002), experiences of inclusion (Whitehurst, 2006), social sexlusion (Morris, 2001), the impact of disability on everyday lives (Stalker & Connors, 2003), general experiences, wishes and feelings (Morris, 2003), and participation in decision-making (Franklin & Sloper, 2006, 2007; Davis, 2007).

Several studies found that eliciting disabled children's views was difficult, time consuming, and required resources, greater planning, and a willingness to try a range of approaches (Taylor, 2007; Watson et al, 2007; Whitehurst, 2006).

But despite greater effort required on the part of professionals, the research suggests that disabled children can articulate their views and should be involved in making decisions about services they use (Kelly, 2003).

As Mortimer (2004, p. 174) stated, "when words and voices are not available, for whatever reason, practitioners need to find ways of 'listening' to children's behaviours and emotional expressions, observing their natural preferences and discovering their individual strengths."

Ware (2004) was alone among the articles reviewed in asserting that the views of some groups may not be attainable. Ware cautioned that some children with high level or multiple impairments could receive a large degree of inference from both professionals and families interpreting their behaviours and reactions.

Disabled children and young people value participation and they have a valuable contribution

As well as having the ability to communicate, research shows that disabled children and young people also have a great willingness to communicate their feelings and experiences and be involved in the process of change (Morris, 2001; Rabiee et al, 2005). When participation occurred, Franklin and Sloper (2007) found that children, young people, parents and professionals viewed it very positively.

Children's increased participation provides more effective programme design and service delivery (Davis, 2007; Mortimer, 2004). Buchanan and Gunn (2007, p. 154) suggested that by "getting involved, children can contribute to the improvement of services by representing their diverse and changing needs and bringing about better informed decisions". Franklin and Sloper (2007) found examples of disabled young people's

voices directly influencing service provision and decisions made within their reviews. Children who were able to participate also expressed feeling listened to, valued and empowered, and were able to gain confidence, self-esteem and learn new communication and collaboration skills (Buchanan & Gunn, 2007; Franklin & Sloper, 2007).

Recommendations for enhancing participation

Recommendations to assist professionals in enhancing the communication and participation of disabled children and young people emerged from this literature.

Advocacy services

Cavet and Sloper (2004) suggested advocacy was one way of facilitating the involvement of disabled children and young people. Advocacy enables people to speak for themselves with support or to have their voice heard through an advocate (Buchanan & Gunn, 2007). Advocacy as a vehicle to promote the empowerment of disabled service users has become increasingly accepted and is widely available in the United Kingdom (Franklin & Sloper, 2006).

Staff training and ongoing development

Increased training and ongoing staff development to promote participation was commonly recommended. The onus lies on professionals to develop and utilise a greater variety of ways to communicate (Rowse, 2007; Westcott & Cross, 1996) and to listen to disabled children and young people (Monteith & Cousins, 2000). Franklin and Sloper (2007) found that children in out-of-home placements particularly needed access to professionals who understood them and provided them with opportunities to express their views.

However, social workers identified that they did not have the necessary skills or confidence for consulting disabled children (Kelly, 2003; Stalker & Connors, 2003) and training was rarely prioritised by managers (Stalker & Connors, 2003).

Recommendations for training included: general issues on participation (Franklin & Sloper, 2007),

inclusion and anti-disablist practice (Griffiths, 2002; Kelly, 2003; Burke & Cigno, 2000), supporting personal growth and development of disabled children and the social model of disability (Willow, 2002), disabled children's right and advocacy (Kelly, 2003), effect of personal attitudes and values on the participation process (Franklin & Sloper, 2007), sign systems and alternative communication techniques (Kelly, 2003), interpreting and presenting children's responses and successfully using interpreters (Franklin & Sloper, 2007).

Franklin and Sloper (2007) additionally recommend that any training should be ongoing and cyclical to accommodate staff turnover, staff development and changing needs such as new caseloads for social workers.

Development of organisational systems and structures

As Franklin and Sloper (2006, p. 726) state, "meaningful participation must be seen as a process, not simply an isolated activity or event." Non-disabling organisational structures and systems are needed to promote the participation process (Cavet & Sloper, 2004; Griffiths, 2002).

Buchanan and Gunn (2007) and Griffiths (2002) discussed the pressures of child protection work and demanding organisational requirements that impair social workers' ability to uphold their clients' human rights to participation. As mentioned, communicating effectively with disabled children takes more time and requires caseload management that allows staff time to develop relationships with children and families and to communicate effectively with other professionals and agencies (Edwards, Vaughn, & Smith Rotabi, 2005; Franklin & Sloper, 2007; Kelly, 2003).

Services need to be well resourced and funded. Edwards et al (2005) argued for better funding for qualified and impartial sign language interpreters and Franklin and Sloper (2006, 2007) argued more resources were needed to monitor and develop a wider range of participation with disabled children.

The literature also recommended improved organisational structures, including clear

protocols and policies to ensure professionals and agencies consulted with disabled children (Kelly, 2003) and recorded the preferred communication methods of children and young people on case files (Franklin & Sloper, 2007).

Community partnerships

Multi-disciplinary, interagency working within the community and partnership with other organisations were also recommended (Burke & Cigno, 2000; Franklin & Sloper, 2007; Kelly, 2003).

The benefits of partnership include shared expertise, ideas and funding and information sharing (Kelly, 2003; Franklin & Sloper, 2007).

Kelly (2003) further recommended joint training between professionals and agencies to ensure that services work collaboratively together.

Information and support for disabled children and their families

Franklin and Sloper (2006) asserted that greater participation requires children and young people to have more support and information about decision-making processes. "Involvement in decision-making becomes more meaningful if children and parents are well informed" (Cavet & Sloper, 2004, p. 285). Franklin and Sloper's (2006) suggested the most likely forms of support to children and young people were assistance with communication, transport and access to venues.

The need to foster positive self-identity, self-esteem and confidence in disabled children was also discussed as a way of encouraging greater participation (Franklin & Sloper, 2006; Westcott & Cross, 1996).

Theoretical considerations

Two key theoretical perspectives – the social model of disability and a human rights discourse – dominated the literature advocating for greater participation.

The social model of disability offers an approach that mitigates the various barriers and social obstacles that hinder disabled children from participation and consultation. Some of the examples of barriers highlighted in the literature

included social exclusion, prejudice and discrimination (Franklin & Sloper, 2006), systemic barriers relating to service provision (Woodcock & Tregaskis, 2008), and social and material barriers (Stalker & Connors, 2003). Morris (2003) and Rabiee et al (2005) found specific barriers and negative attitudes during their research, including adults acting as gatekeepers for children, often citing the children's inability to communicate as a rationale for not agreeing to interviews. Morris (2003) argued the social model of disability provided an opportunity to separate the child's communication needs relating to their impairment (e.g., sign language, equipment) from the disabling barriers created by others (e.g., negative attitudes). This model allows practitioners to acknowledge disabling barriers to communication and an opportunity to safely navigate an alternative approach in order to achieve a positive outcome for the child or young person.

The human rights discourse offers the imperative to ascertain the views and wishes of disabled children, as failing to do so is a denial of their fundamental human rights (Morris, 2001). Articles 12 and 23 of UNCROC outline children's rights to express their views freely in all matters affecting them and disabled children's rights to have active participation in the community.

Professional attitude was seen as key to successful communication. If staff expected to gain little from communicating with disabled children then they were unlikely to gain much (Davis & Watson, 2002; Morris, 2002; Stalker & Connors, 2003; Watson et al, 2007; Westcott & Cross, 1996).

If practitioners start from the assumption that all disabled children and young people can communicate then they are far more likely to achieve the child's fundamental human right to be listened to, to have the right to participate and to be part of the decision-making process (Burke & Cigno, 2000; Morris, 2001; Watson et al, 2007; Buchanan & Gunn, 2007).

Specific techniques for communicating with disabled children and young people

The literature provided specific methods for securing disabled children's involvement and participation, organised here into three headings, engaging and building relationships, communication specific factors, and childcentred approaches for enhancing the child's comfort.

Engaging and building relationships

Engaging and building a relationship with the child or young person with whom the practitioner is working is a fundamental aspect of social work and although building rapport takes commitment and time, it is an essential part of the communication process (Franklin & Sloper, 2007; Griffiths, 2002; Kelly, 2003; Rowse, 2007; Strock-Lynskey & Keller, 2007). As Kelly's (2003) research found, parents were more satisfied with professionals who took the time to develop rapport with their child. Engagement can bring the child's viewpoint into focus (Morris, 2002) and can assist in preparing the child or young person to participate in planned interviews or consultations (Franklin & Sloper, 2007). Engaging in joint activities or games with the child can facilitate rapport building (Franklin & Sloper, 2006; Stalker & Connors, 2003), for instance taking them to the park or bowling (Kelly, 2003).

As a starting point, professionals need to see the child as a child first and disabled second, focusing on the child rather than their impairment (Griffiths, 2002; Stalker & Connors, 2003).

Similarly professionals need to respect and recognise the holistic view of the child including their culture, language, religion, age, gender and disability (Kelly, 2003; Mortimer, 2004). The New Zealand Disability Strategy affirms this perspective, recognising people should not be seen or judged by one aspect of their lives

but rather have their abilities valued and their diversity recognised (Ministry of Health, 2001).

Discussions regarding communication are predicated on the child or young person's consent and willingness to participate (Preece, 2002). This requires children and young people to understand the process and what they are being asked to do (Whitehurst, 2006). Several studies suggested consent required an ongoing process where a child or young person were made to feel they could pass on any questions and could easily stop a session if it was causing distress (Preece, 2002; Stalker & Connors, 2003; Taylor, 2007).

For children with a high level of impairment, the literature advocated observation to ascertain children's views (Franklin & Sloper, 2006, 2007; Morris, 2002; Mortimer, 2004; Taylor, 2007; Ware, 2004), although Taylor (2007) and Ware (2004) warned that observation can be highly inferential. Preece (2002) also recommended observing children in communicative situations to assess their communication abilities.

Communication specific factors

The literature suggested there is no specific communication method that is appropriate for all and each method needs to be individualised for each child and their particular pace and ability (Franklin & Sloper, 2007; Kelly, 2003; Mortimer, 2004; Preece, 2002; Stalker & Connors, 2003; Taylor, 2007; Ware, 2004; Westcott & Cross, 1996; Whitehurst, 2006). As Scammel (2005) points out, even in widely used communication methods, such as New Zealand Sign Language, regional differences exist and children and young people ability levels vary.

Establishing a child's best method of communication and what can be done to enhance their communication requires prior knowledge of the child from people who know them best, including parents, caregivers and families, speech and language therapists, and teachers or residential staff.

(Kelly, 2003; Preece, 2002; Rabiee et al, 2005; Stalker & Connors, 2003; Taylor, 2007; Watson et al, 2007; Morris, 2002; Whitehurst, 2006).

Children may point (with fingers, eyes or instruments) to symbols or signs, or use scanning methods such as grid charts, colour-coded charts, books or auditory scanning. Technological aids may assist children, such as a Liberator,² or human aids such as sign language interpreters (Westcott & Cross, 1996). Ensuring the child has access to their accustomed communication aids is imperative (Edwards et al, 2005; Morris, 2002; Stalker & Connors, 2003; Westcott & Cross, 1996). Practitioners also need to become familiar with different communication aids and how they work (Stalker & Connors, 2003; Westcott & Cross, 1996).

Other useful resources for facilitating communication include:

- i puppets (Franklin & Sloper, 2006; Stalker & Connors, 2003)
- itoys and games (Kelly, 2003; Stalker & Connors, 2003; Watson et al, 2007)
- a doll's house (Stalker & Connors, 2003)
- i paper, pens, craft items (Franklin & Sloper, 2006: Watson et al, 2007)
- i picture symbols and cue cards (Lewis et al, 2008; Preece, 2002; Taylor, 2007; Whitehurst, 2006)
- : role-playing (Franklin & Sloper, 2006)
- if faces depicting a range of different feelings (Kelly, 2003)
- italking mats³ (Taylor, 2007; Whitehurst, 2006).

But as Watson et al (2007) caution, resource kits are useful, but practitioners should be prepared to discard any item that is not working or feels inappropriate. Creative and flexible approaches

² A Liberator is one form of Voice Output Communication Aid (VOCA). It has a keyboard and/or symbols board and a computer 'speaks' sentences inputted by the user (Morris, 2002).

³ Talking mats are resources that aim to enable those with communication impairments to select concrete responses in the form of pictures and place them on a mat to demonstrate their preferences and feelings using either 'like' or 'Dislike' (Whitehurst, 2006).

are needed to listen to children's voices (Mortimer, 2004).

The literature also suggested that although some factually incorrect or partial information may emerge, being able to hear children's voices directly is still valuable, valid and worth the time and effort (Taylor, 2007; Preece, 2002). Practitioners need to persevere and realise at times they may make mistakes or not understand what a child is saying (Morris, 2002; Watson et al, 2007).

When communicating with some children it may be more appropriate to use straightforward closed type questions with single word answers (Preece, 2002; Taylor, 2007), avoid abstract ideas (Taylor, 2007; Morris, 2002), and limit figures of speech, double negatives, and acronyms (Morris, 2002). It is also helpful to slow down, pause, watch and wait for responses (Morris, 2002) and ensure direct eye contact with the child rather than their interpreter, advocate or equipment (Morris, 2002).

Professionals need to be aware of the impact of their own gestures, body language, facial expressions and the behaviours on the children (Whitehurst, 2006).

Child-centred approaches for enhancing the child's comfort

Ensuring that the process is as comfortable as possible for the child or young person being interviewed can reduce their anxiety, increase their confidence and facilitate participation. This can be assisted by:

- involving other adults known to the child (Kelly, 2003; Preece, 2002; Whitehurst, 2006)
- keeping consultation sessions short (Preece, 2002)
- interviewing children in an environment where they feel secure (Morris, 2002; Taylor, 2007; Whitehurst, 2006)
- is selecting a comfortable environment with limited background noise (Morris, 2002)

- i clearly explaining the purpose and anticipated length of the meeting in an introduction letter or e-mail and include a photo of the practitioner (Stalker & Connors, 2003)
- is showing the child positive images of disabled children in a variety of activities (Mortimer, 2004; Stalker & Connors, 2003; Westcott & Cross, 1996).

Providing feedback to the child and their parents/caregivers after the meeting can keep them informed and make them more comfortable the next time (Franklin & Sloper, 2007).

Conclusion

Despite an international shift towards taking into account their perspectives, disabled children are much less likely than other children to have their views listened to by professionals. Furthermore, disabled children and young people not only want to, but are able to communicate their views on a whole raft of topics, whether through verbal or non-verbal means. This premise should be the starting point for all engagements. As Morris (2003, p. 346) sums up:

the most important starting point is to assume that all children and young people – whatever their communication and/or cognitive impairment – have something to communicate. It is up to us to find ways of understanding their views and experiences.

Based on the findings and recommendations of the reviewed literature, a set of practice tips, outlined below, has been developed for social workers to consider when communicating with disabled children and young people for the purposes of seeking and establishing views.

New Zealand's child protection agency has a good foundation for seeking the views of disabled children and young people with legislative, policy and practice requirements in place, as well as obligations through international and local instruments. It is hoped that additional work is undertaken locally on developing ways for practitioners to listen to disabled children, so that this human right becomes embedded in social work practice.

Practice tips for social workers to consider when communicating with disabled children and young people

Before the meeting

- Have I consulted with the child's family, caregivers and professionals about how the child prefers to communicate and what can be done to enhance communication?
- What further advice and information do I require?
- Have I got all the resources/aids I need to facilitate communication?
- What will I need to learn or do in order to use these aids/resources?
- is an independent facilitator, interpreter, advocate or familiar adult required?
- Have I sent the child information (in a format accessible to them) about who I am, why I'm coming to see them, and how long it will take?
- Have I selected a venue that is comfortable for the child and a time of day that will enhance communication?
- Have I considered spending time with the child to observe how they experience things?

During the meeting

- Have I obtained the child's willingness and consent for the interview to occur?
- Have I checked with the child how they will let me know if they wish to have a break or end the interview?
- Have I told the child they do not have to answer questions that make them uncomfortable?
- Have I told the child that there are no right or wrong answers; it is what they think that I want to know?
- Have I ensured I'm looking and speaking directly to the child?
- **:** Am I keeping my language straightforward and limiting my use of things like figures of speech, abstract concepts, double negatives, jargon, and acronyms?
- : Am I proceeding at the required pace?
- Am I considering information that may be generated though the child's gestures, body language, facial expressions and behaviours?
- : Am I thinking about the whole child, and not just their impairment?
- Have I informed the child when I will be next meeting with them?

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