

Supporting Nick to Make Decisions: An Exploration of Ways to Promote Choice and Control

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This article focuses on both the importance and challenges of decision-making for people with intellectual disabilities, using the example of one young man, Nick, as the context for discussion of these issues. Nick is a young man with significant physical and intellectual disability. He has a severe communication impairment and uses a range of Alternative and Augmentative Communication (AAC) strategies to express himself. The article is written by Nick's mother and uses examples from family life to explore the daily tensions in, and opportunities for, choice making.

Communication is at the core of decision-making, and examples of enablers and barriers to successful communication are given. Nick's cognitive abilities impact on the complexity of decisions he can make, the circumstances in which he can make those decisions, and which decisions are relevant and appropriate for him. Supporting Nick in decision making therefore requires an intimate understanding of his personality, his strengths and weaknesses, and what is important to him in his life.

Strategies to support Nick to optimise his success in communication and decision-making are given. Emphasis is placed on the importance of providing opportunities for learning through practice to continue to build capacity for decision-making throughout life.

Keywords: disabilities; social inclusion; communication; staff performance; supported decision-making; support with decision-making

This article was written by the mother of a young man with cognitive and communication disabilities and highlights some of the joys and challenges of supporting him to make decisions about his life. Nick is not able to speak, but has preferences, opinions, questions, ideas, fears, concerns, hopes, dreams, and jokes that he wants to express and share. He has a right to the respect and power that comes from being listened to and having choice and control in his life. Through exploring a range of situations that highlight the challenges Nick has experienced in making and expressing his choices, this article outlines both the importance of supporting him to make decisions and the complexities in doing so. The tension between encouraging choice making and ensuring Nick's safety is explored. Enablers and barriers to Nick's decision-making are discussed, and strategies to enhance his capacity and opportunities for choice making are outlined.

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A Young Man Wanting to Make Decisions

Nick is a 29-year-old man who likes to make his own decisions. Decision-making puts him in control and provides him with opportunities to learn. Supporting Nick to make decisions acknowledges his agency and autonomy, and demonstrates respect for his right to have choice and control over his life.

Nick has strong opinions and expresses his likes and dislikes clearly through his behaviour. There are times when he feels like going out and times when he wants to stay at home; times when he loves the excitement of new experiences and times when he seeks the comfort of the familiar; times when others influence the decisions he makes and times when he wants to take a different path to those around him. There is nothing remarkable in that — these reflect universal needs and desires. However, there are immense challenges for Nick in making those decisions, and sometimes they create seemingly insurmountable barriers.

Nick is an energetic young man, who has strong family connections, precious friendships, and an adored long-time girlfriend. He loves to feel independent, and has a desire for a life of his own, separate from that of his parents. He is spontaneous and impulsive, but his sense of danger and ability to predict consequences are highly variable and dependent on his mood, attention, and focus at the time. He also has cerebral palsy, an intellectual disability, and epilepsy. The impact of these conditions is that he is unable to speak, needs a walking frame or wheelchair to get around, and requires a high level of assistance, support, and supervision to meet his personal care needs and ensure his safety.

Barriers and Enablers: People, Places, and Times

Nick wants, and has the ability, to make many day-to-day decisions, but his disabilities clearly impact on his decision-making capability. His cognitive and communication difficulties mean that he can determine and grasp the implications of some choices, but not others. There are people, places, and times that either facilitate or undermine his capacity to make decisions.

People

Some people are able to listen well and can learn to “hear” what Nick is saying through the many and varied communication strategies he uses (body language, facial expression, vocalisation, gestures, signs, photographs, video, and the fabulous iPad apps that have opened up his world). These people can “still” their own internal voice and “be with” Nick, and imagine the world from his perspective. They can focus on what he has been doing, what interests or unsettles him in his current environment, and what upcoming experiences he is anticipating. On this foundation, they can support him to express himself within the context of that knowledge, using technology, visual, and other available tools.

The essence of the support required is a dialogue of engagement with Nick, continuously checking with him, along the way, one’s understanding of what he is saying. This takes time and persistence, and the willingness to make informed guesses, admit mistakes, and allow Nick to correct them. Approaching communication with Nick in this way is respectful and valuing, whether not his message is fully understood.

There are other people whose internal voices, full of assumptions, judgments, and expectations, drown out Nick’s own. They may have other priorities or their own overriding agenda; they may not take the time or give the focus required; or they may not be willing to take risks, fail to understand, and ask for Nick’s feedback. They may assume they

know what Nick wants to say or may pretend to understand him, while instead overlaying their interpretation of his communication attempts. This is disempowering and devaluing of Nick and his message.

Places and Times

There are places that are calm and quiet; where there is opportunity to explore what Nick wants to say and to expand and develop the conversation. There are times when it is essential to hear as much as possible, directly from Nick, about his feelings, fears, or desires. On other occasions there are other priorities for time and focus. There are places that are too noisy to hear his communication technology; or times when his communication partner is too pressured or preoccupied to focus on his communication. There are also times when it is too dangerous for the communication partner to be distracted by the focus required to understand, when driving for instance.

Decision-making Challenges

Communication

The starting point for choice making is communication, whether intentional or not. The success of Nick's expressive communication depends on his message, motivation, communication aids, and communication partner.

Nick communicates through his body language, facial expression, vocalisation, behaviour, visual cues, and the symbol-based Proloquo2Go App on his iPad. For those who know him, his degree of engagement and enjoyment (or otherwise) is plain to see, and clearly expresses his preferences and the quality of his experience. However, those who are not aware of the many communication strategies he uses often fail to recognise that he is communicating at all.

Nick is a visual learner and communicator. If offered two or perhaps three choices verbally, Nick can choose between them by vocalizing an approximation of the word, but finds it much easier if these choices are represented visually – the object itself, a picture or drawn representation, or even one hand vs. the other.

His visual memory is very strong, so, although he cannot read, when at a restaurant we go through the menu together and I read the choices out, while pointing to them on the menu so he sees where it is written. I observe him closely to see when he is interested in a selection and we narrow down the choices together, until he points to the item on the menu he wants. It takes a while, and requires double and triple checking and rechecking, but choosing from a menu is a great opportunity to control one's life experiences, and to live with the consequences of one's choices!

Nick is a resourceful and creative communicator. Once when I could not understand which staff member he was referring to, he stopped trying to vocalize and signed "rain" – her name was Lorraine. On another occasion, when he was trying to tell a friend about an upcoming trip to Disneyland and was not being understood, he reached into his bag and pulled out an unrelated brochure on the back of which there was a picture of an airplane. This led to a conversation about travelling on a plane, and from there to going to Disneyland! It can take a great deal of energy and focus to get it right – but it is so very rewarding to see Nick's delight – and relief – when he is understood.

If those around him cannot understand, or are not interested in, what Nick is saying, then his choices go unrecognised or are ignored. To enable his decision-making, he needs to have his visual and communication aids with him (and charged), and be with people

who support him to use that aid and are interested in hearing what he has to say. Too often, his aid is not available to him, or people assume they know what he wants and speak for him, or ask him his opinion and then override it anyway.

When Nick feels supported and listened to in his decision-making he feels heard, respected, included, and empowered. This builds his confidence and resilience – and, in turn, this increases his persistence and creativity in the ways he gets his message across.

Conversely, there have been times in his life when he has had trouble communicating with those around him. This has led to a downward spiral of communication failure, becoming disheartened, giving up more quickly, and so failing more often. If this situation continues he eventually shuts down, stops even trying to communicate, and becomes increasingly silent, passive, and withdrawn; or, conversely, he becomes frustrated and angry, lashes out, and is labelled as aggressive, non-compliant, and having “behaviours of concern”.

In summary then, Nick needs those supporting him to **LISTEN**:

- (1) *Learn*: Learn about his communication abilities and preferences; how to use his communication aid; and his repertoire of signs. This provides a foundation for the most important component of learning that occurs through practice in communicating directly with Nick.
- (2) *Interest*: Demonstrate interest in what he has to say. Like anyone else, if Nick feels you are not interested he won't bother trying to communicate with you.
- (3) *Support*: Support him to express himself through the provision of the aids and equipment he needs. Most of the preparation of aids, communication topics, or messages on electronic devices is best done in collaboration with Nick, but some background work (e.g., programming of his device) may be required to ensure he has the support he needs at the time he needs it. Support also includes being available as an engaged communication partner.
- (4) *Time*: It takes time to communicate with Nick, but expressing oneself and being heard is central to recognition, inclusion, empowerment, dignity, choice making, participation, and contribution. Providing those opportunities is fundamental to care and support.
- (5) *Encouragement*: Nick has experienced communication failure on many thousands of occasions in his life. These are disempowering and devaluing experiences and he does not want to repeat them, and so he gives up if he feels he will not be listened to or understood. He knows when people are able, willing, and interested in listening to him.
- (6) *Notice*: Nick's communication is often subtle. His communication partner needs to be focused on observing facial expression, body language, gestures, and signs. He gives great feedback! It is readily apparent if you have understood him as he becomes more engaged and animated. Conversely, if you have missed the point he may give up, disengage, and withdraw.

Cognition and Consequences

Nick has difficulty conceptualising and understanding abstract notions such as time and the future implications of decisions, and so the consequences of certain decisions either do not occur to him or seem irrelevant.

The responsibility for choices with potentially serious implications, such as those involving health issues (dietary choices, the need for surgery), accommodation (where and with whom he lives), criminal behaviour (shop lifting), risk taking (e.g., walking down a train line) must be taken by those supporting Nick. He should always be involved as much as possible in making the decisions that affect him and his views and preferences should be central. The implications of the choice should be discussed with him, but respecting him as an individual includes accepting him as he is, and this includes understanding his cognitive impairment. Having an intellectual disability means that he cannot conceptualise the implications of various decisions. Therefore, taking responsibility for major life decisions is a fundamental duty of care of those supporting Nick.

Another abstract concept with which Nick has difficulty is the concept of money. When choosing a gift for a friend, for instance, providing him with choice is essential – but the range of choices should be narrowed to those consistent with an appropriate choice within a reasonable budget. We, therefore, talk together before we go shopping about what sort of gift may be appropriate – books, perfumed products, socks, CDs, for example. Then we go to a shop and I choose four or five items consistent with the requirements we have discussed (person, product, price) from which he can choose.

Cognition and Complexity

Some decisions are just too complex for Nick to play a primary role in making, although he should always be included in discussions around the options. Surgeries for the musculoskeletal implications of his cerebral palsy are examples of these decisions, and these are heart-wrenchingly difficult for family to make on his behalf. Any procedure has potential benefits and risks. The decision to go ahead or not is a complex risk-benefit analysis, an informed judgment dependent on the weighing up of probabilities. Most of Nick's surgical procedures have resulted in pain and short-term loss of function for an anticipated long-term improvement. This is very hard to explain to him, and it can be agonizing to watch his face express his confusion, and even betrayal, as he struggles to understand why I have subjected him to the fear, stress, and pain of surgery and its aftermath.

We have been fortunate; most of Nick's surgical procedures have gone well and have clearly been of benefit to him and have not had long-term adverse effects. Others we know have not been so fortunate, and the person and their family live with long-term pain, loss of function, and impaired quality of life and perhaps the uncertainty, regret or even guilt as to whether they made the best decision.

On one occasion, Nick's surgery was successful on one leg and not on the other. It resulted in Nick going from walking independently to not being able to walk at all for more than six months. I had told Nick that the operation would help him walk. I recall vividly one day when he sat on his bed and cried as he pointed to his leg and shook his head – saying "This leg doesn't work." I cried too. I felt so very sad for him, and deeply responsible and guilty.

Cognition and Change

Change is often very difficult for Nick. He likes the patterns and routines in his life. He enjoys anticipating what will happen next – and asks repeatedly for the reasons if a routine changes. Anticipation is a central element of Nick's quality of life. Events such as Christmas, birthdays, Easter, visits to and from friends, dates with his girlfriend, and upcoming movies or stage shows provide him with months of pleasure in the anticipation and preparation. He has an iBook (made with the iPad App Book Creator) of the movies

on this year, and can use this to say what he has been to and what is coming up. This book also provides him with a way of choosing which movie he would like to see next. Other iBooks describe holidays or other social and family events, either past or anticipated. These give him access to ways to share his experiences, both past and future, in some depth, with those important to him.

When prepared in advance for an event, he derives enormous pleasure in reflecting on the upcoming experiences both alone and with others. He will use his communication App, iBooks, or other visual aids to think about the event by himself, as well as using these tools to share his excited anticipation with others.

Challenges can arise when an opportunity arises unexpectedly as he may find the rapid change in plans required just too difficult to accommodate. This happened recently when we had a last-minute opportunity to go to *Les Miserables* at Her Majesty's Theatre in Melbourne. Nick adores musicals, and I was very excited that we had tickets; I knew he would love the show. But I was not able to prepare him ahead of time as we had had the tickets for just over an hour before the curtain was to rise. I tried to discuss it with him, but he would not engage in the conversation, nor answer my questions – he just tuned out and pushed me away. When the taxi came, at first he refused to get in and it took about 10 minutes of vigorous encouragement, firm direction, and bribery before he reluctantly agreed to climb into the vehicle and sit in the seat.

Once in the taxi, I found the songs from the musical on YouTube on my phone and played them to him all the way to the theatre. That preparation helped enormously and he relaxed and loved the whole experience. He reminded me of other musicals we had seen at that theatre – *Mary Poppins*, *Chitty Chitty Bang Bang*, *Mamma Mia*, *Phantom of the Opera*, and *Love Never Dies* – by pointing to pictures on his iPad and even showing me where he had stood and sat on some of those visits.

He was completely spellbound by the show, wanted the merchandise, and wore the hat and T-shirt continuously for a week (we washed it at night and put it on damp in the morning!). He listened to the music on his iPad constantly, and we bought the movie and he watched it about 20 times over a few days. That was three months ago, and the *Les Miserables* program, DVD, and music are still favourites. He regularly reflects on and reminds us of the show by selecting and looking at the iBook we made of the experience.

Going to the musical was a wonderful, enriching experience to share with Nick, and one that has given him many months of pleasure. But it was not his choice when offered the opportunity. His choice on the day was to stay at home. To “respect” his choice on that occasion would have been an all-too-easy choice, but would have denied him a powerful and highly rewarding experience. I knew that he would love it, and that knowledge came from knowing him well and was based on sharing many experiences with him over the years.

I talked with him afterwards about it, and tried to help him explore the consequences of deciding to go or not to go. I do this often, in the hope that it will support him to better understand the implications of the decisions he makes. I do not know if we are making progress in that regard, but I think it is important to keep trying.

Relevant and Real Choices

Choice making also depends on relevance and engagement. There are things that are important to Nick and there are things that are not important. For instance, he is usually not very interested in what he wears. The important exception is when he is going to a special occasion – visiting a friend's house, a date with his girlfriend, a friend's birthday, a Christmas or Halloween party. Then he is passionately interested in what he will wear and is actively involved in the choice of outfit. He often wants to start with the tie – and

then I select two or three shirts from which he can choose that could go with that tie. We often have to hang the outfit on the outside of the wardrobe door a week in advance – it is all part of the joy of anticipation.

To make choice making relevant and real, Nick's choices must be acted upon. Sometimes people will engage in theoretical discussions of "*would you like to one day . . . ?*" or "*wouldn't it be great if we could . . . ?*". These concepts are far too abstract for Nick. If he says "yes", and everyone laughs and the conversation moves on, I see him looking confused and hurt. Choices should only be offered if they are real and there is an intention to follow through on them. If Nick's decisions are not acted upon, then his choice becomes meaningless.

Duty of Care and Dignity of Choice and Risk

Making choices about one's life, and having these respected by others, promotes the sense of agency and dignity. However, not all choices offered are valid or responsible.

At one point, Nick was regularly being offered food choices for lunch or dinner such as: "*Would you like a sausage roll or pie?*" Is that a meaningful choice reflecting the range of food on offer? Is it a choice that builds experience and knowledge? Is it a choice that promotes a healthy lifestyle?

Outings to fast food outlets are sometimes offered as a choice; for instance, a choice of dinner at McDonalds or KFC? As occasional events these may be harmless enough, but as regular occurrences I do not see them as appropriate. The defining of what is a "treat" is highly subjective, and unhealthy food should not be presented as desirable. We are not talking about teenagers who may indulge in these for a few years until their tastes and understanding of the importance of a healthy diet develops. We are talking about adults for whom this eating pattern can last for decades.

Offering unhealthy dietary choices is not in line with the duty of care with respect to optimising Nick's health and function. He is of normal weight, but borderline with respect to his ability to walk. If he becomes overweight he will lose his ability to walk independently, which will impact enormously on his independence, care requirements, and quality of life. Likewise, regular energetic exercise is essential to Nick retaining optimal muscle strength, function, and independence in mobility. Nick cannot foresee the consequences of unhealthy food choices and inadequate exercise; it is up to those supporting him to understand this is part of their duty of care. A healthy diet and regular exercise are fundamental requirements of care and not matters of choice.

So, What Do We Need to Do to Support Nick's Decision-making?

- (1) *Acknowledge his right* to make choices and decisions about his life.
- (2) *Recognise his ability* to make many decisions when given the appropriate support.
- (3) *Involve those who know him well* to better understand who Nick is, what he wants and enjoys in his life, how decisions have been made in the past, and how to best include Nick in meaningful decision-making.
- (4) *Understand his communication abilities*, and provide him with the equipment he needs and a communication partner who will work hard to understand him.
- (5) *Encourage choice making* whenever and wherever possible to provide opportunities for him to practice and learn.
- (6) *Respect his choice* to enable him to experience the consequences when safe and appropriate to do so. This is an important step in learning what making decisions means.

- (7) *Discuss decisions and their consequences* with Nick (and key people in his life where appropriate). Nick's cognitive impairment means that he finds it difficult or impossible to predict or imagine the implications of some choices. He therefore needs a great deal of support in thinking through and reviewing the consequences of decisions to build his capacity in this regard.
- (8) *Ensure choices are relevant and responsible*. Respecting Nick includes understanding who he is, what is important to him, and the choices that are within his ability to make.
- (9) *Appreciate that there are some decisions that are too complex*, or the consequences of which are too serious, for Nick to make. Respecting Nick includes recognising both his abilities and his disabilities. Supporting choice making does not abrogate duty of care.
- (10) *Recognise that decision-making ability is not static*. Capacity and capability may be undermined by lack of appropriate communication tools or communication partners, lack of confidence or self-esteem, presence of ill-health, pain or discomfort, or the experience of anxiety or distress. Conversely capacity and capability can be built through encouragement and opportunities for practice and learning; and are strengthened by appropriate support.

In Conclusion

Choice making is a skill that requires opportunity and practice to learn. Making relevant choices that have real life consequences is empowering and enables control over one's life.

There are choices that are **important to Nick**, such as the choice of friends, meals and activities. Enabling and supporting Nick to make these choices demonstrates respect and values his autonomy. Choices carry with them the risk of good or bad outcomes. This is the essence of the Dignity of risk.

There are other choices that are **important for Nick**, such as the achievement and maintenance of optimal mental, physical, social, and financial health and function. This is the essence of the Duty of Care.

Understanding and respecting Nick, and appreciating both his abilities and the impact of his cognitive and communication difficulties on his decision-making, informs finding the right balance between autonomy and support. The goal is to promote Nick's capacity and opportunity to experience choice and control, and so to enable him to live a life full of the experiences and relationships he chooses.

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