

Supporting Nick to make decisions
A personal exploration of choice

La Trobe Roundtable on Supported Decision Making
Dec 10, 2014

Jane Tracy

Nick likes to make decisions. To make decisions about his life puts him in control. They also provide him with opportunities to learn.

Making decisions enables Nick to feel his agency and autonomy is recognised and his choice and control respected. He has strong opinions and expresses his likes and dislikes. There are times when he feels like going out and times he feels like staying home. Times when he likes the excitement of new experiences, and times when he likes the comfort of the familiar. There are times when his decisions are influenced by others, and times when he wants to take a different path to those around him. There's nothing remarkable in that – these are universal needs and desires. However, there are some immense challenges for Nick in making those decisions, and sometimes they are insurmountable.

Nick is an energetic young man, who has strong family connections and friendships, an adored long time girlfriend, and a desire for a life of his own, separate from his parents. He also has cerebral palsy, an intellectual disability and epilepsy. The impact of these conditions are that he is unable to speak, and needs a walking frame or wheelchair to get around. He is impulsive and his sense of danger is variable and dependent on his mood and focus at the time.

What this means for Nick's decision-making is that there are implications of decisions he can grasp, and others he can't; and there are people, places and times that either facilitate or undermine his ability to make decisions.

- **People:** Some people are able to still their own internal voice and 'be with' Nick where he is; to look at the world from his perspective; to consider what he has been doing and what is coming up in his life; to work with him to support him to express himself within that context; and to check with him to see if they have understood correctly. Then there are other people who have other priorities and their own overriding agenda; who assume they know what Nick wants or wants to say; and who pretend to understand while instead laying their interpretation over Nick's communication attempts. The former approach is respectful and valuing, the latter disempowering and devaluing.
- **Places and times:** There are places and times that are calm and quiet; where there is time to explore what Nick wants to say and to expand and develop the conversation; or where it is essential to hear as much as possible directly from Nick about his feelings, fears or desires. And there are places and times that are too noisy to hear his communication

program; or too pressured and busy to enable focus on the communication; or too dangerous to be distracted by the effort required to understand; or too exciting for Nick to want to communicate in any way but pointing!

Challenges in supporting Nick's decision-making

- **Communication:**

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

Nick communicates through his body language, facial expression, vocalisation, behaviour, visual cues and picture based Proloquo2Go 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. But those who are not aware of the many facets of his communication, often fail to recognise 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 have a visual representation – the object itself, or a picture or drawn representation of the object of choice, or even one hand vs the other or fingers of one hand.

His visual memory is very strong, so although he can't read, when at a restaurant we go through the menu together and I read the choices out while pointing to that choice 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 that he wants. It takes a while, and requires double and triple checking and rechecking, but choosing from a menu is a great opportunity to live with the consequences of your choice!

Nick is a resourceful and creative communicator. Once when I couldn't understand which staff member he was referring to, he stopped trying to vocalize and signed 'rain' – her name was Lorraine. When he was trying to tell a friend that he is going to Disneyland next year and he was not being understood, he reached into his bag and pulled out a brochure on the back of which there was an ad for Emirates. This led to a conversation about going on a plane, and from there to Disneyland. It can take a great deal of energy and focus to get it right – but it is so rewarding to see Nick's delight and relief when he is understood!

If those around him can't understand, or are not interested in, what Nick is saying, then his decisions are unrecognized or ignored. To enable his decision making then, 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 powerful. This builds his confidence and his resilience – and his persistence and creativity in the way he gets his message across.

However, at times in his life when he has had trouble communicating with those around him, he has tended to give up more easily and eventually has either shut down and withdrawn into himself or has become angry, lashed out at people and been labeled as having Behaviours of Concern.

In summary then, Nick needs those supporting him to LISTEN

- **Learn:** Learn about his communication abilities and preferences. Some of this learning occurs through communicating with Nick, other learning of particular systems may need to be done at another time in preparation.
- **Interest:** Demonstrate interest in what he has to say. Like anyone else, if Nick feels you are not interested he will stop trying to communicate with you.
- **Support:** Support him to express himself through the provision of the aids and equipment he needs. Some of the preparation of aids, communication topics or messages on electronic devices etc is best done in collaboration with Nick, but some may need to be made or programmed at another time to ensure he has the support he needs at the time he needs it. Support also includes being available as an engaged communication partner.
- **Time:** It takes time to communicate with Nick, but expressing oneself and being heard is central to recognition, inclusion, dignity, choice making, participation and contribution. It is fundamental to care and support.
- **Encouragement:** Nick has experienced communication failure on many occasions. These are disempowering, and devaluing experiences and he doesn't want to repeat them, and so he gives up if he feels he won't be listened to or understood. He knows when people are able, willing and interested in listening to him.
- **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**

Nick has difficulty conceptualizing and understanding abstract notions such as future implications of decisions, and so the consequences of certain decisions either don't occur to him, or seem irrelevant.

The responsibility for choices with serious implications, such as those involving health issues, accommodation, criminal behaviour, risk taking (e.g. walking down a train line), must be taken by those supporting Nick. He should always be

involved in making the decisions that affect him and the implications of the choice discussed with him, but respecting him as an individual involves accepting him as he is, and this includes understanding his cognitive impairment. Having an intellectual disability means that he cannot conceptualize the implications of various decisions. Taking responsibility for major life decisions is therefore part of the 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 a reasonable budget. We therefore talk about what sort of gift may be appropriate before hand – books, perfumed products, socks, CDs etc – and then we go to a shop and choose up to 5 items consistent with the requirements (person, product, price) from which he can choose by pointing.

- **Complexity**

Some choices are just too complex for Nick to make. Surgery for the musculoskeletal implications of his cerebral palsy are examples of these. These decisions 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 risk benefit analysis, an informed judgement and weighing up of probabilities. Many 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 sense of confusion about why I have subjected him to the surgery and its aftermath.

We have been fortunate, most of Nick's surgical procedures have gone well and have had great benefit for him without long term adverse effects. Others are not so fortunate and the person and their family live with long term pain, loss of function and impaired quality of life.

On one occasion, the 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 for more than 6 months. I had told Nick that the operation would help him walk. At one point 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.

- **Change**

Change is often 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 really important aspect 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 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 also provides him with a way of choosing which movie he would like to see.

When prepared in advance for an event, he derives enormous pleasure through sharing the anticipation with others and thinking about it himself. He will often use his communication device or visual aids to reflect on upcoming events by himself, as well as to share with others.

Difficulty can arise when an opportunity arises unexpectedly. He is likely to refuse the opportunity, because the rapid change in plans is just too difficult for him to accommodate. This happened recently when we had a last minute opportunity to go to Les Miserables at Her Majesty's Theatre. Nick adores musicals, and I was very excited for him that we had these tickets and I knew he would love the show. But I was not able to prepare him ahead of time as we had the tickets just 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 zoned out. When the taxi came he refused to get in. It was really difficult and it took 10 minutes, but eventually we got him in - with a combination of encouragement and direction and bribes. Once in the taxi, I got the musical on YouTube on my phone and he watched it all the way in to the Theatre and thereafter loved the whole experience. He reminded me of other musicals we had seen there – Mary Poppins, Chitty Chitty Bang Bang and Mamma Mia. He was transfixed by the show, and wore the hat and Tshirt for the next 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 has watched it about 20 times. It was a wonderful, enriching experience to share. But it was not his choice on the day. His choice on the day was to stay at home. To 'respect' his choice on that occasion would have been to deny him an experience I knew from past experience that he would love. I talked with him afterwards about it, and tried to help him think about what would happen if he had decided not to go and what happened when he decided 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 don't know if we are making progress in that regard, but I think it's important to keep trying.

- **Relevance**

Choice making depends on relevance and engagement. There are things that are important to Nick and there are things that are not. He is not very interested, for instance, 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 or Christmas 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 choosing 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 wardrobe a week in advance – its part of the joy of anticipation.

- **Duty of care and Dignity of choice**

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 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 health?

Outings to fast food outlets may be offered, with a choice, for instance, between McDonalds and KFC? As occasional events these may be harmless enough, but as regular occurrences, often presented as special treats, I do not see these as appropriate choices. They do not fulfill the requirements for duty of care with respect to optimizing Nick's health and function. Nick is of normal weight, but is 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. Nick cannot foresee this kind of consequence, and it is up to those supporting him to understand this is part of their duty of care. A healthy diet and adequate regular exercise are fundamental requirements of care, as is dental hygiene, and should not be a matter of choice.

The defining of what is a 'treat' is highly subjective, and unhealthy food should not be presented as a desirable event. We are not talking about teenagers who may indulge in these for a few years until their tastes and understanding of the importance of diet develops. We are talking about adults for whom this eating pattern can last for decades.

So, what do we need to do to support Nick's choices?

1. **Acknowledge his right** to make decisions about his life
2. **Recognise his ability** to make decisions when given the appropriate support.
3. **Involve those who know him well** to understand who Nick is, and what he wants and enjoys in his life, how decisions have been made in the past and how to best include Nick in decision making.
4. **Understand his communication** abilities and needs, and provide him with the equipment he needs and a communication partner will work to understand him.
5. **Encourage choice making** whenever and wherever possible to provide opportunities to practice and learn.
6. **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. Supporting choice making does not abrogate duty of care.
7. **Respect his choice** to enable him to experience the consequences. This is an important step in learning about what making a decision means.
8. **Reflect and discuss decisions and their consequences** with Nick and key people in his life, where appropriate. Nick's cognitive impairment

means that he has difficulty imagining some of the implications of decisions difficult and he needs a great deal of support thinking through and reviewing the consequences of decisions to build his capacity in this regard.