

Tips for leading a discussion about working with families – ‘Jane’s Story’

The following guide has been developed to assist disability service providers using ‘Jane’s Story’ as part of a professional development activity for staff regarding working with families.

Introduction

- 1** There is a range of ways that ‘Jane’s Story’ can be used. Two suggested uses are:
 - a. As part of your organisation’s orientation / induction program for staff.
 - b. As part of a broader review of your organisation’s approach to working with families.
- 2** The questions and prompts outlined below represent some of the key areas of the story that we recommend facilitators explore with staff. Facilitators are encouraged to adapt the discussion in line with the time available, the learning needs of staff, the type of staff development activity being conducted and/or specific practice areas relevant to services delivered by the organisation.
- 3** Depending on participant numbers and the type of training activity being delivered, consideration should be given to whether the discussion/s are conducted in one large group or smaller breakout groups. There are pro’s and con’s to each.
 - a. Small group activities generally facilitate higher levels of participation, however consideration needs to be given as to how the small group discussions will be monitored and supported.
 - b. Large group activities generally require less staff to monitor the discussion and can provide opportunities for staff to hear a broader cross-section of views. A drawback is that some staff can find such groups intimidating to actively contribute.
- 4** Some people have found elements of ‘Jane’s Story’ emotionally confronting. Given this, when leading a discussion with staff about the issues raised in the film, we recommend that consideration be given to how staff who become upset during the discussion will be supported.

Key learning outcomes

We suggest that key learning outcomes for staff that ‘Jane’s Story’ could be used to achieve include:

- The importance of family in the life of the person with a disability and the importance of that person to the family.
- The challenges families may experience at different points in the family lifecycle when one family member has a disability.
- Organisational practices relevant to working with families and the implications for the person with a disability.

Working with families – ‘Jane’s Story’: Questions for group discussion

Suggested questions	Areas / issues to cover
<p>Ask participants for their initial reaction to the film:</p> <ul style="list-style-type: none"> • from a personal perspective • from a professional perspective – did it change the way they think about the people they work with? Did it change the way they think about the families of those with whom they work? 	<ul style="list-style-type: none"> • The importance of engaging with / listening to / seeking input from / actively involving families. • Appreciation of the love and commitment of family members, and their lifelong involvement in the lives of their sons and daughters (whether they have a disability or not, and tends to be more intense involvement in the former).

Key learning outcome – 1	
<p>Jane talks about the need to support Nick’s communication skills and opportunities as a basic and fundamental area critical to his support.</p> <ul style="list-style-type: none"> • Given how Nick’s story turned out, what are the main lessons you will take away from this part of the story in relation to your role as a support worker? 	<ul style="list-style-type: none"> • The importance of getting to know the person, and that means learning how to best communicate with him/her. • Not to be too quick to label someone as having behaviours of concern. Appreciate that behaviour is a communication, and it is important to consider carefully what may be behind a change in behaviour. Look past a person’s behaviour and try to understand what they’re experiencing and what their behaviour is ‘telling’ you. • To seek input from people who know the person intimately and/or for a long time (family, friends etc). They may better understand how the person communicates and what this change in behaviour may mean. • Not to dismiss the opinions of people who know the person better just because you don’t agree with them. • That all staff working with the person have a responsibility to understand how to best communicate with them and how to support their ability to communicate. This includes learning about how to use and create the person’s communication tools, whether ipad based or otherwise. Family members will often be happy to provide training.
<p>Having heard Jane’s and Nick’s story:</p> <ul style="list-style-type: none"> • What do you think are some of the important benefits of families remaining actively involved in the life of their family member with a disability? 	<ul style="list-style-type: none"> • Being part of a family is part of identity and creates a sense of belonging. • Families are part of building and maintaining a social network that goes beyond paid staff. • Social (unpaid) networks of family and friends remain involved over time. Staff tend to come and go in people’s lives. Building and maintaining these long term relationships builds resilience and is an important way of safeguarding rights. • Family members have an intimate knowledge of the person and their history. This is information is vital to getting to really know the person, and in problem solving when issues arise. • Someone other than paid staff advocating for the person.

<ul style="list-style-type: none"> • If Jane hadn't advocated as she did for Nick, what are some of the ways Nick's life might have turned out differently? 	<ul style="list-style-type: none"> • Lack of support with his communication – isolation and lack of social engagement. People who try to communicate and are not understood, eventually give up trying. • Misperception of his behaviour. If Nick's behaviour was labelled “a behaviour of concern”, and not understood as a communication of his loneliness, sadness, grief, boredom and frustration, then there is a risk that restraint (mechanical and/or chemical) may have been used. This would have negatively impacted on his engagement, well-being and happiness, and overall quality of life.
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Key learning outcome – 2

<p>Jane describes receiving information about Nick's diagnoses and disabilities as a 'series of body blows'.</p> <ul style="list-style-type: none"> • What do you think she meant by this? • How do you think Jane's perception of Nick's future might have changed during this period? • If you were to put yourself in Jane's position, what do you think you'd be feeling emotionally? 	<ul style="list-style-type: none"> • A sense of grief / loss / concern for her son and his well-being. Each diagnosis (epilepsy, cerebral palsy, intellectual disability) named another set of challenges and barriers Nick would face to inclusion and participation; developing and maintaining relationships; and in creating a rich, engaged and fulfilling life. • Potential negative impact on Nick's life experiences and opportunities – a sense of loss / fear / uncertainty for Nick and for herself.
<p>Jane recalls a time when she rang the group home to ask about Nick's well-being and overhearing the staff member asking someone else “Which one's Nick?”.</p> <ul style="list-style-type: none"> • If you were in Jane's situation, how do you think this conversation might have impacted on your interactions with the staff / organisation? • As a staff member, what do you think you could do to increase people's confidence in the support being provided to their family member? 	<ul style="list-style-type: none"> • Fear/concern that staff did not know, let alone care about, my loved one. • Loss of trust and confidence in staff and the organisation. • Feeling the need and responsibility to: <ul style="list-style-type: none"> ◦ Be more involved in monitoring day to day health and other issues, ◦ Be more vigilant in supervising support and care being provided, and ◦ advocate more energetically to ensure your family member's rights and well-being are being respected. • Actively engage with and get to know each individual. • Proactively and openly communicate with each person's family. • Seek their involvement and input. • Be transparent about what's going well and not so well. • Families can be partners with you in understanding and addressing the needs of the people with whom you work, and in troubleshooting and brainstorming solutions to issues that arise.

Key learning outcome – 3

Jane describes how she felt she was ‘abrogating her responsibility’ and ‘abandoning him to the care of strangers’, when she sought accommodation support for Nick.

As individual staff, and as an organisation, what can you do to:

- Support families during the transition of their son or daughter into supported accommodation?
- Support and maintain the families involvement in the life of their family member with a disability?

- Whenever possible and whilst respecting the wishes of the person with a disability:
 - Involve family as much as possible in their ongoing support
 - Actively seek input from family
 - Support the family’s decision to seek help and through the transition period
 - Support the ongoing relationship with family through regular contact and time together.
 - Support the person to initiate and maintain contact with their family (e.g. birthdays, special events)
 - Invite the family to the person’s new home for meals, special events, and any time they want to drop in.
- Train staff around the importance of families in the lives of the people with whom they work.
- Provide clear guidance, support and supervision for staff in relation to working with families.

Jane talks about being nervous about making a formal complaint about Nick’s support.

- What are some of the reasons people might be reluctant to make a complaint?
- How can people be supported to feel comfortable to provide feedback / make a complaint?

- Fear of retribution or loss of support for Nick.
- Fear of loss of services.
- Fear of not being believed – having to ‘prove’ the case.
- Concern about being labelled as difficult.
- Previous negative experiences with complaints.
- Lack of knowledge about the complaint process and uncertainty about the right to complain, and the benefits of doing so.
- Openly demonstrating a policy and culture of welcoming feedback and complaints as ways of continuing to improve the service.
- Regularly asking people for their feedback about what is and is not working for their family member and their family.
- Formal and informal opportunities to provide feedback.
- Acknowledging that the service may not be perfect and that their feedback can help to improve things.

<p>Towards the end of the story Jane states “Then something really big changed”.</p> <ul style="list-style-type: none"> • What did Michelle do, and how did she make Jane feel, that turned the situation around? • What implications does this have for how staff and/or the organisation works with families? 	<ul style="list-style-type: none"> • Michelle made the time and effort to sit and listen to Jane to understand her concerns. • Jane felt listened to / that her concerns had been heard and validated / that someone had taken the time and interest to listen to her concerns (respect) / had acted on Jane’s concerns (‘doing what needed to be done’). • Once they’d built up a rapport, Michelle also let Jane know when she disagreed with her; once trust was established then honest and frank discussions were possible. <p>For staff / the organisation:</p> <ul style="list-style-type: none"> • Proactively engage on a regular basis with families. • Acknowledge the importance of the family’s role in the life of their family member. • Build rapport and trust. Only in an atmosphere of trust and respect can difficult issues be discussed and resolved without defensiveness and blame becoming barriers to honest exchanges of perspectives and views. • Be clear about your expectations of each other, and honest about what is and is not possible. • Address people’s concerns or explaining what the barriers are to solutions that may be unrealistic in current circumstances. • Ensure that commitments and decisions are followed through and reviewed.
<p>Finishing the discussion</p> <ul style="list-style-type: none"> • Ask participants to identify the one thing they will take away from the film / discussion that they can use to change their practice tomorrow. • Reaffirm your organisation’s approach to working with families and to the importance – and benefit – of listening to and acting on people’s concerns and complaints. 	

Using ‘Jane’s Story’ as part of reviewing your organisation’s approach to working with families

Drawing on the questions related to ‘Jane’s Story’ and areas identified in Disability Services Commissioner’s Occasional Paper No. 2: Families and service providers working together:

- What does your organisation do well?
- What could your organisation do better?
- What will you prioritise for further action (either building on what you do well or addressing what you could do better)?