



VOICES OF INDIVIDUALS: Collectively Exploring Self-determination

Guidelines for Pairs



This project has received funding from the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme grant agreement no 638768. This publication has been produced with the assistance of the European Union. The contents of this publication are the sole responsibility of VOICES project and can in no way be taken to reflect the views of the European Union

Table of Contents

Contacting Your Paired Person	3
Agreeing a Way to Work Together	3
Preparing for your next workshop	5
At your next workshop	5
The Role of Storytellers	6
The Role of Respondents.....	6
The Role of Supporters	7
The Role of Mentors	7
Legal and Ethical Responsibilities.....	8
Potential Difficulties.....	9
Key Dates	10

Contacting Your Paired Person

Once you have been informed of the storyteller or respondent you have been paired with, you will receive contact details for that person along with information about that person's preferred way of being contacted (e.g phone, email, or post). This information will be taken from the application forms storytellers and respondents sent to the VOICES research team in March 2016. The VOICES research team can help to set up initial conversations and discussions between pairs if required.

This might include setting up skype conversations or agreeing to meet in person if you live near each other. If you would like the VOICES team to help set up an initial conversation for your paired person, please email us at ercvoices@nuigalway.ie to let us know. We ask all pairs to schedule their initial conversations within 2 weeks of being notified of their pairing and to inform the VOICES team once this has occurred. If we haven't heard from you within a month, we will check in again to see if you need any support in setting up your initial conversation.

Agreeing a Way to Work Together

In your initial conversation as a pair, it is important to agree on how you plan to work together. At a minimum, we would expect each pair to have a conversation via skype, phone, or in person, at least once a month. In your first meeting you should set out what each of you expects from the pairing, what your goals are in working together, what your strengths are individually and as a team, and what supports you will need to do your work together.

Here are some ideas to consider as you plan your work together:

- How often do you want to meet?
Discuss how you want to work together, what kind of communication works best for meetings (phone, skype, in person) and keeping in touch in between meetings (email, post, etc.) The VOICES project does not currently have funds for travel in between workshops, but we are actively seeking funds for this,

and would appreciate any ideas participants have about sources of funding for this travel.

- Who will take notes of your meetings?
Respondents might agree to do this, or it could be shared so that respondents and storytellers take turns writing the notes of each meeting. Decide how to share these notes with each other (e.g. email, post, etc.)
- How do you want to tell your story?
You might want to spend some time writing your ideas first, or developing them with a supporter or member of the VOICES team, before sharing them with your respondent. Think about the people you will write about in your story and check the section below on legal and ethical responsibilities for more information.
- How do you want to prepare your response?
You might want to work on your ideas after you see a draft of the story, or give the storyteller some ideas as you go along.
- How much input do you expect to have on the other person's work?
Storytellers may want to give feedback and shape the respondent's ideas and approach. Storytellers might also ask respondents for ideas in shaping and developing their story. The level of involvement on each side will be up to each pair to decide.
- What do you expect the final written piece to look like?
It could be a stand alone story followed by a separate response, or have the story interwoven with the response, or another format that you both agree on that can be published in a book. Each pair's contribution to the book should be no more than 5000 words in total (including footnotes).
- Are there any good examples of writing you have seen which includes both a story and a response?
Please share these with each other and decide if there is anything you can use from these examples. The VOICES team will also create a Dropbox folder so that everyone can share these resources.

Once you have made decisions on each of these issues, draw up a plan for working together and send it to the VOICES team. We will arrange for regular discussions between each pair and the VOICES team to make sure everything is going well. If you have any questions or concerns arising from your meetings, please let the VOICES team know.

Preparing for your next workshop

In the feedback forms from the April workshop, all storytellers listed which workshop they want to attend to tell their story. This information will be shared with each storyteller's respondent so you can plan together for the next workshop. Please check the dates for each workshop listed below, on page 10, and tell the VOICES team if you have any problems with these dates. Before your next workshop, you should write-up a draft of your story and an outline of your response based on your monthly meetings.

To help pairs prepare for next workshop, the VOICES team will circulate an issues paper on that topic a month before the event. This issues paper will set out some of the legal and policy issues on the topic of the workshop. For example, an issues paper for the criminal responsibility workshop will set out some of the problems with current laws on the insanity defence and fitness to plead from the perspective of the UN Convention on the Rights of Persons with Disabilities. These papers will guide storytellers and respondents on how they can develop their ideas for the workshop and their contribution to the book.

At your next workshop (and afterwards)

The private day will take place first, before the public day, to give the pairs more time to get used to working together before they present in public. On the private day each pair will give an update on how they are developing their story and response for feedback and ideas from the other workshop participants. The VOICES team will arrange travel and accommodation for each pair to attend the workshop. If needed, the VOICES team will plan travel arrangements to allow each pair time to meet up together before and after the workshop to prepare for the event and to plan their next steps.

On the public day, each pair will be invited to give a summary of their story and response. The VOICES team will work with each pair before the event to help prepare their presentations for the public day of the workshop. You do not have to present on the public day if you do not want to. After your next workshop, you should continue to work on your story and response, based on the feedback you received from the other pairs. You will be expected to have prepared a full draft of your story and response in time for the book editing workshop in November 2017.

The Role of Storytellers

- Choose the parts of your story that are most relevant to the issue you have decided to focus on (e.g. contract, consent, etc.)
- Decide what you want to share and what you want to keep private.
- Consider the implications of naming and identifying people and places in your story (especially where your story is not already in the public domain, or reflected in the facts of a legal case).
- Think about what you and others can learn from the story you are sharing in the VOICES project.
- Discuss the respondent's ideas and give them constructive criticism and feedback.

The Role of Respondents

- Listen respectfully and accept the storyteller's perspective – it is their experience and you are in the privileged position of having this experience shared with you.
- You might need to learn more about the storyteller's legal, political, social and cultural systems in order to understand their story. Ask the storyteller where you can find the information you need.
- Discuss with the storyteller what worked well for them in the story they are sharing (for example, peer or family support) and what did not work well or what could have worked better.
- Together with the storyteller, work to place their story in a broader context. Where else does this happen? What are the

factors that are contributing to this situation? How can we change this if it needs to be changed?

- Think about the big picture – what would be needed to make sure this story is, or is not repeated (depending on whether it was a positive or negative experience). What reforms to law, policy and practice are required to reflect Article 12 of the UN Convention on the Rights of Persons with Disabilities?

The Role of Supporters

Some storytellers have chosen support people who they have asked to help them throughout the project. Other participants might need support but not have a chosen supporter they want to help them. If you would like someone from the VOICES team, or another person, to act as a supporter for you in your pair, please contact ercvoices@nuigalway.ie to let us know.

The role of supporters is to facilitate smooth communication between the storyteller and respondent. This might involve providing communication support for the storyteller, keeping notes of discussions with the respondent, helping the storyteller to write down their ideas and prepare for meetings with the respondent, or follow up on tasks agreed at the meeting with respondents.

In some cases, due to language barriers, supporters may be providing translation or interpretation for storytellers. Some storytellers may prefer to have a separate translator or interpreter and not to use their support person in this way. If you need a translator or interpreter as well as a supporter to enable you to work with your paired person, please contact ercvoices@nuigalway.ie to let us know.

The Role of Mentors

Pairs can ask for a mentor to support them in their work, and provide guidance and advice where needed. Pairs may also be assigned a mentor by the VOICES team. Mentors will usually be drawn from the VOICES Advisory Board and Steering Group, but external mentors might be approached if required (e.g. due to language skills or specific knowledge of a particular issue or context). The role of the mentor will vary based on each pair's needs. Some pairs might ask the mentor to attend all their meetings, while others might just want

to check in with their mentor once every few months. If you have not already requested or been assigned a mentor, discuss at your initial meeting whether you as a pair would like to have a mentor, and if possible, consider whether there is a particular person from the VOICES Advisory Board or Steering Group who you believe could be a good mentor for you, or whether there is an external person you would like to approach. If you would like to have this option, please contact the VOICES team to request a mentor by emailing ercvoices@nuigalway.ie .

Legal and Ethical Responsibilities

The VOICES project asks all co-authors in the edited collection (storytellers and respondents) to adhere to the highest ethical standards as they develop their research. Given the intimate and potentially painful nature of the experiences which participants may be recalling, sharing and writing about in their pairs, it is possible that some people, either respondents or storytellers, could experience discomfort or distress. In order to minimise potential risks entailed in sharing stories which detail unhelpful or obstructive behaviour by other parties (particularly families, employers, and other close supporters, including medical, social care and legal professionals) on whom people may remain dependent, either emotionally or economically, certain caution will be required to anticipate and minimise damage to such relationships through sharing very personal material.

All co-authors in the final VOICES book should be aware of the risks of litigation being initiated by parties who could deem themselves defamed by the disclosure of information in a particular story. Further, all participants must make themselves aware of their legal obligations to disclose certain kinds of information (e.g. concerning the commission of crimes) to the relevant authorities. Given the obligations of researchers under Irish law, if participants share information relating to certain kinds of criminal offences (sexual offences, human trafficking or false imprisonment) **committed in Ireland**, the VOICES team should be informed and will be obliged to disclose the relevant information to the Gardai Siochana (police).¹ If you have any questions or want to clarify the extent of these

¹ See section 2, Criminal Justice (Withholding of Information on Offences against Children and Vulnerable Persons) Act 2012.

obligations, please contact the VOICES team.

The legal and ethical obligations of working together will be explained to each pair at the outset of the research process by the VOICES team. Each pair is responsible for raising these issues as they arise (e.g. discussions about what kind of information to disclose in the story), for advice and guidance from the VOICES team. Dedicated space will be provided at each thematic workshop, and in the book-editing workshop in November 2017, to discuss these legal and ethical issues in further detail.

The VOICES team will endeavor to ensure that all pairs are fully aware of any potential libel risks in what is published. The risks involved will be discussed at each workshop with all of the pairings so they can decide what they would like to include in their pieces. Once a contract for the book is secured, pairs will be given information on any requirements imposed by the publishers on the format or content of information which can be published, and the legal consequences that could result for the book editors, publishers and authors. The VOICES team will remind participants that the written word is potentially a very powerful and permanent record, as well as a tool for change.

Potential Difficulties

What to do if you have difficulty working in your pair -

- Tell the VOICES team.
- Raise the issues with your mentor if you have one, or ask about getting a mentor for your pair.
- If you feel someone in the pair is not fulfilling their role, or is being prevented from participating by someone else, contact the VOICES team.
- If you decide you no longer want to work together, let the VOICES team know.

If a storyteller decides to leave the project what will happen?

All participants can decide to leave the project at any time, without giving reasons. If a storyteller leaves the project, no part of their

story will ever be published by the VOICES project. The respondent who was working with that storyteller will be invited to contribute to the project in a different way. This might include writing a different kind of contribution for the VOICES book, a journal article for a special issue, or a blog post for the website.

If a respondent decides to leave the project what will happen?

All participants can decide to leave the project at any time, without giving reasons. If a respondent decides to leave the project, the VOICES team will work to find an alternative respondent for the storyteller, so that the story and a response to it can still be included in the VOICES book. If this is not possible, the storyteller will be invited to present their story in a different way, perhaps in a journal article for a special issue or as an oral presentation at a VOICES workshop, or through making a video for the blog.

Key Dates

The dates for the events are as follows –

- Criminal Responsibility Workshop – 22nd & 23rd September 2016
- Contractual Capacity Workshop – 17th & 18th November 2016
- Consent to Treatment Workshop – 23rd & 24th February 2017
- Consent to Sex Workshop – 11th & 12th May 2017
- Final Workshop – November 2017
- Deadline for submitting final contributions to book – January 2018
- Concluding Conference – October 2018