Independent advocacy in action:

Case studies illustrating SIAA's 'Principles and Standards'

2021



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### Introduction

SIAA publishes a set of 'Principles, Standards and Code of Best Practice', developed to be used across Scotland to ensure that independent advocacy is being delivered consistently and to the highest possible standards. It describes:

- Three principles which underpin all independent advocacy work
- Eight standards, which slot under the principles and provide additional context and detail
- Forty-four indicators, some aimed at independent advocates and some aimed at independent advocacy organisations. Together, these make up the Code of Good Practice and demonstrate how the principles and standards translate into real-life policy and practice

The document is aimed at independent advocacy organisations to support them in their work and to offer a means by which they can evaluate their practice. However, in addition to supporting independent advocacy organisations themselves, the 'Principles, Standards and Code of Best Practice' is also aimed at:

- People who could benefit from independent advocacy so that they have a clear idea about what to expect from an independent advocacy organisation
- those who commission, fund and regulate independent advocacy to ensure they have a clear understanding of what independent advocacy is, and how independent advocacy organisations should operate

The principles, standards and indicators are detailed in Appendix 1 on page 45-47.

To support our key stakeholders to get the most out of the Principles document – particularly those with less first-hand experience of independent advocacy – SIAA has created this series of case studies.

Each case study documents an issue or issues brought by an advocacy partner or group and details what support the independent advocate provided, as well as identifying which elements of the Principles document the case illustrates. Note, because the three high-level principles underpin all independent advocacy work, we have not highlighted these in relation to each case study. Instead, we delineate the specific standards and indicators illustrated by each case, as these will vary depending on issues and context.

The intention is for readers to use both documents - the 'Principles' and the 'Case Studies' – in conjunction with one another. The case studies put 'flesh on the bones' of what independent advocacy looks and feels like, and demonstrate how the 'Principles, Standards and Code of Best Practice' should be effectively woven through organisational policy and day-to-day working practices.

## Case study 1 - Focusing on the advocacy partner

Rachel and Ailsa are parents to a daughter who had recently been taken into care. An independent advocate helped the couple to understand their rights as parents as well as the process surrounding their daughter being taken into care.

Rachel and Ailsa are a couple in their early 40s, with a six-year-old daughter, Leah. They have been drug users for many years and are participants on a methadone programme. Concerns raised by Leah's school had led to her being taken into care because of risks that she was perceived to be exposed to. This included her parents' ability to care for her, as well as her living environment and the presence of other adults who were often in the family home.

The advocate supported Rachel and Ailsa to understand their rights as parents and to communicate their wishes, ensuring that they were heard throughout the process. This included their intention to maintain the lifestyle that they had, which was creating high potential risk of harm to Leah. Although the advocate themself believed this to be true, they did not express this at any point or let it influence the independent advocacy they provided. Equally, the advocate did not validate Rachel and Ailsa's choices. The advocate was able to support Rachel and Ailsa to understand the policies on which decisions were being based, how their choices would affect the outcomes, and the processes which were ongoing for Leah's care and how they were likely to proceed.

This case study illustrates the following Standards:

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.

- Indicator 1: Enable your advocacy partner or advocacy group to understand their rights and ensure that they are recognised by others.
- Indicator 3: Reflect on your practice and be aware of your own opinions, prejudices and discriminatory views and values and not let them affect your practice.
- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- Indicator 13: Practice and promote effective communication with your advocacy partner or advocacy group, especially when they may face barriers.
- Indicator 14: Not take the side of anyone other than your advocacy partner or advocacy group or try to influence them on behalf of others.
- Indicator 15: Ask decision makers to explain why an action is taken where required.

## Case study 2 - Supporting better communication

An independent advocate worked with a man who found it difficult to express his wishes when engaging with people and services in his life. The independent advocate helped him to understand his options and build skills to better communicate.

Xinran was 31 and troubled by a number of issues. He had debts with credit card companies, was in trouble with his landlord for non-payment of rent and had recently had a dispute with a neighbour. He openly admitted that any time he tried to solve these problems with the various individuals or organisations he would end up getting angry, argue with whoever he was dealing with and fail to reach any positive conclusion. As a result of this, Xinran believed that no-one was interested in him, or was prepared to listen to his point of view.

The advocate spent time with Xinran and together they made a record about what he hoped to achieve with each situation and considered the various possible outcomes. Next, they held an initial meeting for each situation during which Xinran was supported to express his views in a constructive way. Following these meetings, the independent advocate gave him time to reflect and comment on progress, as well as identify what he wanted to do next. Gradually, Xinran was able to work towards each of the outcomes he had hoped for.

Over time, with the independent advocate acting as a role model in preparing for and participating in meetings, Xinran became confident in being able to express himself. He was eventually in a position to attend meetings and represent himself using his newfound skills and confidence.

This case study illustrates the following Standards:

- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.

- Indicator 10: Enable your advocacy partner or advocacy group to outline, record and review their expectations.
- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- Indicator 16: Ensure that you seek and are guided by feedback from your advocacy partner or advocacy group members.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.
- Indicator 18: Make every effort to enable your advocacy partner or advocacy group members to have the opportunity to develop skills and confidence to advocate for themselves.

### Case study 3 - Establishing a viewpoint

A care home referred an older man with a dementia diagnosis to independent advocacy. An independent advocate worked with him to establish his views and wishes about his living situation.

Billy was in his 80s and, after a lifetime working on farms, lived in a local care home. He had dementia which had progressed to a moderate degree. Staff at the care home had received comments and concerns from some members of Billy's family, who lived some distance away, that he was unhappy with aspects of his care. They said they were considering moving him to a home, closer to where they live. The staff believed that this would be unsettling for Billy, as it would remove his current opportunities for having visitors from a local church he was involved with, in an area he was familiar with. Care home staff were unable to establish what specific things he was unhappy with. They also recognised that, while the family had no legal powers, they faced a conflict of interest in getting Billy's views and discussing the situation with them.

The care home asked an independent advocate to help establish Billy's level of satisfaction with his current living arrangements and his desire to move elsewhere. The advocate recognised that Billy had very little power in the situation and worked to build a rapport with him in order to gather views that were as accurate as possible. Billy often talked about work as if he still played an active role in farming, discussing the deployment of workers needed and what each job would involve.

The advocate took time to talk with Billy over several visits, reminiscing over his farming past to develop a rapport & making him feel relaxed. Then, as part of the conversation, it became possible to ask Billy about how comfortable he was in the home, whether he was sleeping well, what he thought of the food, and whether he felt anything needed to change. He was also shown photos of his most regular two visitors,

about whom he talked positively. From this, the advocate was able to evidence that Billy's views of his current living arrangements were consistent and positive. This information was then shared by the advocate at a scheduled care home review, to ensure it was taken into account. It enabled Billy's views to be heard and considered, even if his contribution at the meeting may be limited, due to his capacity.

This case study illustrates the following Standards:

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.

- Indicator 11: When advocating in a non-instructed context, make significant efforts to determine the rights, will and preferences of your advocacy partner, and where this is not genuinely practicable then make certain that decisions are taken with due consideration. for their unique preferences, rights and perspectives.
- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- Indicator 13: Practice and promote effective communication with your advocacy partner or advocacy group, especially when they may face barriers.

## Case study 4 - Identifying barriers and renegotiating a situation

Providing independent advocacy to a Black Scottish woman detained under the Mental Health Act and dealing with institutional racism within the mental health system. Independent advocacy worked with her to have her voice heard and articulate her wishes.

Grace was a 24-year-old woman who was keen to leave hospital. She was frustrated by the fact that this was not possible as she had been detained under the Mental Health Act. Grace's Mental Health Officer had concerns that the decision to detain Grace had been made on the basis of two short consultations which recorded that she was extremely agitated and aggressive. He noted that this perception could be the result of institutionalised racism which would make medical staff more likely to interpret Grace's behaviour as hostile and threatening because she is a black woman.

Grace had originally been brought into hospital by the police when she was very unwell, but reported that she was feeling significantly better. However, she felt that she had been unable to communicate effectively that her mental health had improved – in fact, she said that the hospital processes had been very stressful for her with the consultations themselves being at the root of her agitated behaviour. Grace's GP had provided additional evidence that supported her detention but, as Grace had had no recent contact with her, there was a question about the validity of the information.

Grace met with an independent advocate who identified that a range of barriers, including a lack of staff time and institutionalised preconceptions and biases about race, had created a power imbalance

where Grace's voice was no longer heard. The independent advocate took time to explain their role and, in particular, evidence the independence of the advocacy service within the hospital. This was important to Grace, as she had had frequent negative experiences with mental health services in the past.

At the same time, Grace was given notice of a Mental Health Tribunal Scotland (MHTS) hearing, which might have resulted in her stay in hospital continuing. She received the notification letter on a Friday with the hearing due to take place on the following Monday. The reason given for the short timescale was that this was the only slot available before the expiry date of the current order. This caused Grace significant stress, as well as leaving her with almost no time to prepare, or access advice and representation. Her independent advocate provided 'same-day' support to Grace and called MHTS to make clear that the timescale was unsuitable, and requested that the hearing be rearranged.

Over the longer term, with the support of the independent advocate, Grace wrote a statement reflecting on her current mental health, experiences of racism during her appointments at the hospital and her hopes for the future. At a subsequent consultation, she was able to use this document - which clearly set out her preferences in her own words to articulate herself and regain some power over the situation. Grace was informed of her right to complaint about the service at the end of the meeting. The document also formed the basis of Grace's Advanced Statement, setting out her preferences, wishes, beliefs and values regarding her future care, which she worked on with her independent advocate.

This case study illustrates the following Standards:

• Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.

- Standard 1b: Independent advocacy must be able to evidence and demonstrate its structural, financial and psychological independence from others.
- Standard 1c: Independent advocacy provides no other services, has no other interests, ties or links other than the delivery, promotion, support and defence of independent advocacy.
- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.
- Standard 3c: Independent advocacy challenges discrimination and promotes equality and human rights.

- Indicator 2: Ensure your work promotes equality and challenges discrimination.
- Indicator 4: Identify and challenge any attitudinal, structural or environmental barriers to accessing, using or taking part in independent advocacy.
- Indicator 10: Enable your advocacy partner or advocacy group to outline, record and review their expectations.
- Indicator 13: Practice and promote effective communication with your advocacy partner or advocacy group, especially when they may face barriers.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.

### Case study 5 - Using assistive technology to develop an Anticipatory Care Plan

An independent advocate used 'Talking Mats' to communicate effectively with a 62-year-old-woman with impaired cognitive functioning and verbal communication. They worked together to develop an Anticipatory Care Plan, which later helped doctors to make decisions about her care when her condition worsened.

Fiona was a 62-year-old woman with alcohol-related brain damage (ARBD), which had resulted in impairments of cognitive functioning and verbal communication. Her sister, who was her primary carer, felt that she would benefit from independent support to express her views regarding her current and future care, most notably through the development of an Anticipatory Care Plan. Fiona met with an independent advocate who took time to establish a relationship with her, looking at aspects of Fiona's life and her interests using photos and a diary book which had been previously compiled. The independent advocate also established permission from Fiona to develop a working relationship with her sister, who was also next of kin and power of attorney. The independent advocate never withheld from Fiona any of the information she got during the conversations with her sister.

The advocate used Talking Mats over a number of meetings, to establish Fiona's views on a range of matters including options for her accommodation and care, both currently and in the future. Talking Mats was also used to establish Fiona's views on the potential progression of her condition and medical interventions which might take place at different points. This established an Anticipatory Care Plan to be used in such events. Fiona's sister was keen to review the decisions and suggest some changes but, when the Anticipatory Care Plan was double-checked with Fiona, she did not want to alter any of her choices.

Some months later, Fiona was admitted to hospital as her condition had worsened. The Anticipatory Care Plan she had produced proved crucial in supporting medical professionals to make a decision to halt treatment at a particular point, because they were in possession of Fiona's clearly expressed views.

This case study illustrates the following Standards:

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.

- Indicator 6: Not withhold information from your advocacy partner.
- Indicator 9: Act on the issues agreed by your advocacy partner or advocacy group at the appropriate pace.
- Indicator 10: Enable your advocacy partner or advocacy group to outline, record and review their expectations.
- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- Indicator 13: Practice and promote effective communication with your advocacy partner or advocacy group, especially when they may face barriers.
- Indicator 14: Not take the side of anyone other than your advocacy partner or advocacy group or try to influence them on behalf of others.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.

### Case study 6 - Using legislation to protect a man with a learning disability

A young man with a learning disability had been taken advantage of by people he thought were his friends and run up debts as a result. The independent advocate met Craig in his home, where he felt more comfortable, and then liaised with a number of mobile phone companies to explain that he had been exploited to take out the contracts and lacked capacity to understand the consequences of his actions.

Craig was an 18-year-old man with a learning disability. He had been groomed by some people he thought were his friends to sign up for a number of mobile phone contracts. Craig did not understand what he was committing to and became very anxious when he started receiving letters demanding payments. His social worker referred him to an independent advocacy organisation to support him to address the issue.

The independent advocate who first met with Craig realised that he had previously supported one of the people who had been exploiting Craig. He flagged this to his manager, in line with the organisation's 'conflict of interests policy', and the case was taken over by a colleague.

The second independent advocate met Craig at his home, where he felt less upset and stressed and therefore better able to communicate and explain the situation. She established that Craig had 12 mobile phone contracts with different providers but did not actually have any phones in his possession. Craig explained that he had given the phones as presents to people he thought of as his "friends" to thank them for spending time with him. The independent advocate contacted the phone companies to explain the situation and that Craig lacked capacity to

understand what he was doing when he took out the contracts. Some of the companies were quick to write off the debts. The independent advocate is still liaising with the remaining companies.

This case study illustrates the following Standards:

- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.

- Indicator 1: Enable your advocacy partner or advocacy group to understand their rights, and ensure that they are recognised by others.
- Indicator 4: Identify and challenge any attitudinal, structural or environmental barriers to accessing, using or taking part in independent advocacy.
- Indicator 7: Look out for, declare and minimise conflicts of interest in line with the organisation's conflict of interest policy.

### Case study 7 - Supporting a child and upholding confidentiality

A high school student who had been experiencing Islamophobic bullying was being supported via an independent advocacy dropin session at her school. The independent advocate upheld her confidentiality and, as requested, did not contact her parents.

An independent advocacy service has a regular drop-in session at the local high school. Samena was a 13-year-old British Egyptian girl who had been receiving ongoing support from an independent advocate as she had been experiencing Islamophobic bullying from her fellow pupils.

Samena was very clear from the offset that she did not want her parents to know about the bullying or the independent advocacy support, as she did not want to them to worry. The independent advocate worked with Samena and therefore respected her views by not making any contact with her mum and dad.

However, her mum found out about the situation when she was chatting with another parent in the playground. She was worried about the bullying and angry with the independent advocate for not getting in touch with her. She contacted the independent advocacy organisation and said that, as Samena's mother, she had a right to be informed and consulted. The independent advocate explained that this was not the case and that independent advocacy always places the person it is working for in the centre and stands by their views and wishes. In addition, the organisation has a specific policy which requires upholding Samena's confidentiality.

The advocate contacted Samena as soon as possible to tell her about the conversation they had had with her mother. They also reminded her of the organisational policy around confidentiality to reassure Samena that no information about her situation had been shared.

This case study illustrates the following Standards:

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 3c: Independent advocacy challenges discrimination and promotes equality and human rights.

This case study illustrates the following Indicators for advocates:

- Indicator 2: Ensure your work promotes equality and challenges discrimination.
- Indicator 6: Not withhold information from your advocacy partner.
- Indicator 8: Uphold the confidentiality of your advocacy partner in line with the organisation's confidentiality policy including being honest when the policy should be breached.

# Case study 8 – Collective advocacy: Consensus, confidentiality and campaigning for change

Enabling people with mental health diagnoses living in supported accommodation to take action and bring about meaningful change, through a facilitated collective advocacy group.

'We Want Change' was established as a collective advocacy group supporting people with mental health diagnoses living in supported accommodation. It aims to ensure that the residents can come together, find a collective voice and act together to influence agendas and

decisions that affect their lives.

The group started after some of the residents shared concerns with each other that it was hard to have a relationship - all of the rooms only had single beds, and staff had told them that there was 'a rule' that partners were not allowed to stay over. The residents felt that this was not fair and that they were being discriminated against. A group of them worked together to find an independent advocate who could help support them to take collective action by facilitating their meetings.

The group initially established ground rules which were largely focused on confidentiality both within group discussions as well as how these conversations and those attending were presented in minutes which were available externally. The group then worked on practicalities such as agreeing the location and format of future meetings to best suit those attending and developed a group identity and brand. These early discussions created 'We Want Change' and enabled those attending right from the start to own and direct the group. The group created a space for people to find ways to describe and make sense of their experiences and develop consensus on priorities for action. The independent advocacy worker was able to use her community development skills to enable the group to learn from each other, explore new possibilities and become more effective collective agents of change.

One of the early meetings enabled 'We Want Change' members to have a question and answer session with senior service managers. This provided a clear way of breaking down barriers, ensuring that the group's voice was heard, identifying future actions and enabling a collective movement for change. The group has also worked for positive change by raising issues with the Mental Welfare Commission and the Care Inspectorate.

This case study illustrates the following Standards:

• Standard 1a: Independent advocacy follows the agenda of the people

- supported regardless of the views, interests and agendas of others.
- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.
- Standard 3c: Independent advocacy challenges discrimination and promotes equality and human rights.

- Indicator 1: Enable your advocacy partner or advocacy group to understand their rights, and ensure that they are recognised by others.
- Indicator 2: Ensure your work promotes equality and challenges discrimination.
- Indicator 5: Address any power imbalance between yourself and your advocacy partner or the advocacy group, or within the group.
- Indicator 8: Uphold the confidentiality of your advocacy partner in line with the organisation's confidentiality policy including being honest when the policy should be breached.
- Indicator 9: Act on the issues agreed by your advocacy partner or advocacy group at the appropriate pace.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.
- Indicator 18. Make every effort to enable your advocacy partner or advocacy group members to have the opportunity to develop skills and confidence to advocate for themselves.

- Indicator 19: Make every effort to support an advocacy group to debate and reflect on the views and experiences of the group members as well as agreeing issues to take forward.
- Indicator 21. Support the advocacy group to define and agree the internal and external boundaries of confidentiality.

### Case study 9 – Working to defend a young person's right to education

A young man with ADHD and ODD and mild ASD in the fourth year of high school had been told he should collect and sign his leaver's form but that he had not been excluded. He was supported by an independent advocate to learn about his rights to access education and additional support and to meet with his deputy head teacher to discuss his options.

Brian and his mum contacted an independent advocacy organisation as Brian had been asked by his deputy head to collect and sign a leaver's form and told he could not attend the winter ball. Brian did not want to leave school and had planned to complete 5th year, so he refused the leaver's form. He was panicked as he thought he must have been excluded.

Brian's mum informed the independent advocate that she had been requesting additional support for Brian since his transition to high school, but that it had not been forthcoming.

The independent advocate shared information with Brian about his rights to attend and engage with education. The advocate established, from speaking to the deputy head, that Brian was not officially excluded 23

but that the school thought it best for him to engage in college or work instead. With the support of the independent advocate, Brian was empowered to meet with the deputy head and ask why the decision to give him his leaver's form had been taken and ask that his rights be upheld. The legal information and guidance relating to exclusion and additional support was shared with the school. Shortly after this meeting, Brian was given a new timetable with support to complete his studies. He was also delighted to attend the winter ball!

#### This case study illustrates the following Standards:

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.
- Standard 3c: Independent advocacy challenges discrimination and promotes equality and human rights.

- Indicator 1: Enable your advocacy partner or advocacy group to understand their rights, and ensure that they are recognised by others.
- Indicator 2: Ensure your work promotes equality and challenges discrimination.
- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.

- Indicator 15: Ask decision makers to explain why an action is taken where required.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.
- Indicator 18: Make every effort to enable your advocacy partner or advocacy group members to have the opportunity to develop skills and confidence to advocate for themselves.

### Case study 10 – Independent advocacy for a parent who had children in kinship care

Independent advocacy for a 34-year-old mother whose two children had been removed from her care and placed in kinship care due to Child Protection concerns relating to the mother's alcohol misuse. She required support from independent advocacy to manage Child Protection meetings and to access a solicitor.

Marnie was a 34-year-old woman with alcohol misuse issues. Her misuse of alcohol precipitated a crisis situation, involving Child Protection processes and her children being moved into kinship care. Marnie's eldest child was living with her father, Marnie's abusive ex-husband. Her younger child was living with Marnie's adoptive family, where Marnie had experienced childhood sexual abuse.

The crisis situation uncovered decades of abuse, denial, avoidance and coping/managing behaviours relating to poor mental health stemming from the abuse Marnie had experienced when she was younger.

Independent advocacy supported Marnie to understand Child Protection processes, access a solicitor, report historical sexual abuse, attend Child Protection meetings feeling prepared, find her voice, and not to judge herself too harshly, but to own her mistakes and remain engaged in the processes in order to challenge most effectively.

As a result, Marnie's younger child returned to live with her and work to return her older child to her as well was ongoing. Marnie has now been in recovery for over 10 months - she is employed, a full-time parent, exploring her creative talents and forming healthy, stable relationships.

This case study illustrates the following Standards:

- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.
- Standard 3c: Independent advocacy challenges discrimination and promotes equality and human rights.

- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.
- Indicator 18: Make every effort to enable your advocacy partner or advocacy group members to have the opportunity to develop skills and confidence to advocate for themselves.

### Case study 11 – Transitioning out of the forensic mental health system

Independent advocacy was provided for a young man whose illness presented as him being withdrawn and non-engaging. The independent advocate worked to build a relationship and discovered that he had lost touch with his family some years previously. They worked with him to communicate with professionals and agencies in order to re-establish contact with his siblings, nieces and nephews.

Jon was a young man who had been unwell for a number of years, although this had gone undetected and untreated. This resulted in several incarcerations and difficulty maintaining contact with his family. The independent advocate worked with Jon to build a trusting relationship and discovered that, apart from the professionals working with him, he had no other support in place. It was agreed that making contact with Jon's family was a key priority for him.

The independent advocate pursued a number of avenues, including speaking with his social worker, liaising with the Salvation Army and working on a budgeting plan with Jon that would allow him to access his birth certificate. The advocate also ensured good communication with his doctor, social worker and nursing staff so they were aware of what was happening, as Jon lacked the confidence to communicate with key staff himself.

Working with the Salvation Army, they were successful in contacting his sister. The independent advocate then worked with Jon to write a letter to her, as he felt unable to complete this alone due to a lack of literacy skills. This form of contact was facilitated until he felt comfortable taking forward contact by telephone.

The work of the independent advocate helped Jon to start re-building a network of social support, beyond the professionals that were already in place. Jon feels hopeful that this will help him to move confidently through the forensic mental health system and back into the community.

This case study illustrates the following Standards:

- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.

- Indicator 9: Act on the issues agreed by your advocacy partner or advocacy group at the appropriate pace.
- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- Indicator 13: Practice and promote effective communication with your advocacy partner or advocacy group, especially when they may face barriers.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.
- Indicator 18: Make every effort to enable your advocacy partner or advocacy group members to have the opportunity to develop skills and confidence to advocate for themselves.

### Case study 12 – Collective advocacy collecting views on mental health crisis care in Highland

A round of pan-Highland collective advocacy meetings was conducted to collect the views of 135 mental health service users on their experiences of crisis and crisis care. A full report was published online and sent to key targeted decision-makers.

An independent advocacy organisation located in the Highlands conducted a round of pan-Highland collective advocacy meetings, to collect the views of 135 mental health service users on their experiences of crisis and crisis care.

The process started with an invited meeting of service users, to help determine their priorities. The top priority was crisis care, with service users feeling that too much resource was being spent on recovery and self-management programmes at the expense of immediate, accessible crisis response and care. This situation was particularly acute in remoterural and rural areas of the Highlands.

Meetings were then held at ten rural locations and with local Invernessbased groups. A report was produced which recorded all the voices from the meetings and summarised both positive and negative views. It also included anonymised case studies and references to relevant statistics, such as current Highland-wide suicide rates.

The report was published online at <a href="https://www.spiritadvocacy.org.uk/resources">www.spiritadvocacy.org.uk/resources</a> and circulated widely to key decision-makers, including local and national NHS staff.

The work of the independent advocate helped Jon to start re-building a network of social support, beyond the professionals that were already in place. Jon feels hopeful that this will help him to move confidently through the forensic mental health system and back into the community.

This case study illustrates the following Standards:

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.

- Indicator 4: Identify and challenge any attitudinal, structural or environmental barriers to accessing, using or taking part in independent advocacy.
- Indicator 8: Uphold the confidentiality of your advocacy partner in line with the organisation's confidentiality policy including being honest when the policy should be breached.
- Indicator 16: Ensure that you seek and are guided by feedback from your advocacy partner or advocacy group members.

### Case study 13 - Empowering a visuallyimpaired advocacy partner to build positive relationships

Jerry was a 58-year-old man with a visual impairment who had been served with an eviction notice from his local authority landlord. An independent advocate worked with him to help establish effective two-way communication channels with the relevant services and ensured that Jerry received information in accessible formats.

Jerry was a 58-year-old man with a visual impairment who lived alone and described himself as a contented loner. He came into conflict with his local authority housing office when his block of flats was due to have all the windows replaced. Jerry's flat was so full of his belongings that the carpenters were unable to access his flat to carry out the repairs and, as a result, he came into conflict with a housing officer. There was a rapid breakdown in communication and the police became involved which culminated in his prized - and fully licensed - firearms being confiscated and his being served with an eviction notice.

Jerry was deeply distressed about the situation when he accessed independent advocacy support. He had not received any communications from the local authority or police in an accessible format and was therefore confused and scared by the situation.

The independent advocate arranged a meeting with a housing officer and was able to open a dialogue where Jerry felt heard, as well as being helped to understand the local authority's position on safety. They also ensured that Jerry received information he could access by providing it as a tagged pdf compatible with his screen reader technology. He felt enabled to allow housing staff to visit him in his flat and advise him on

how to manage all his possessions safely. The local housing office agreed to reverse the eviction process. The independent advocate then liaised with the police Firearms Unit and agreed a detailed plan to have his guns returned.

Jerry now has a good, established relationship with both the housing office and the police and is happy to request additional support from them, if needed. He also receives all his information from the housing office in formats that are accessible to him, which has enabled Jerry to have his Article 9 right (under the United Nations Convention on the Rights of Persons with Disabilities) to accessible information realised. He feels empowered to stay calm in meetings, have his opinions heard and ask for help when he requires it.

This case study illustrates the following Standards:

- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.
- Standard 3c: Independent advocacy challenges discrimination and promotes equality and human rights.

- Indicator 1: Enable your advocacy partner or advocacy group to understand their rights, and ensure that they are recognised by others.
- Indicator 2: Ensure your work promotes equality and challenges discrimination.

- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- Indicator 13: Practice and promote effective communication with your advocacy partner or advocacy group, especially when they may face barriers.
- Indicator 15: Ask decision makers to explain why an action is taken where required.
- Indicator 16. Ensure that you seek and are guided by feedback from your advocacy partner or advocacy group members.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.

### Case study 14 - Ongoing independent advocacy supporting and empowering a 15-year-old girl

Megan was a 15-year-old girl, in hospital on a community treatment order (CTO). Independent advocacy supported her to appeal the CTO successfully and continued working with her to achieve a number of other positive outcomes.

Megan is a 15-year-old girl, who was in hospital on a community treatment order (CTO). She self-referred to independent advocacy as she had a Mental Health Tribunal coming up to vary her CTO. The independent nature of the advocacy was very important to Megan, as

she had previously had negative experiences with mental health and social work services. The independent advocate supported her through the whole process and the CTO was not renewed.

The relationship between Megan and the independent advocate continued, with support being provided in a number of ways, including during Children's Hearings procedures, during social work 'looked after and accommodated' reviews, reintegration back into school and considering housing and career options.

The independent advocate helped Megan to communicate to all the agencies involved and to give her own views. At the start of the process, she was very shy and quiet and struggled to speak with others. Advocacy empowered her to have the confidence to speak out and not be afraid, as well as to believe that her views and opinions really do matter.

The independent advocacy relationship supported Megan in achieving many positive outcomes – her Compulsory Supervision Order (CSO) was terminated at a Children's Hearing, her CTO was removed, she reintegrated into education and moved into a new home. Overall, Megan feels she is now living a very different life and is confident moving forward knowing that independent advocacy will be there to support her if and when she needs it.

This case study illustrates the following Standards:

- Standard 1c: Independent advocacy provides no other services, has no other interests, ties or links other than the delivery, promotion, support and defence of independent advocacy.
- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.

- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.

This case study illustrates the following Indicators for advocates:

- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.
- Indicator 18: Make every effort to enable your advocacy partner or advocacy group members to have the opportunity to develop skills and confidence to advocate for themselves.

### Case study 15 – Supporting an advocacy partner to take effective action

Independent advocacy for a man in his late forties recovering from problematic substance use. The local authority had been stalled for many months on repairing his bathroom because of an administrative issue. He was supported in contacting the local authority and getting the issue sorted, directly resulting in the desired repairs being carried out.

Malcolm was a man in his mid-forties recovering from an opioid addiction. He approached the independent advocacy organisation for support corresponding with the local authority's housing repair department.

Many months before he sought this advocacy support, Malcolm had been having work carried out on his council house. Whilst carrying out the repairs, workmen discovered drug paraphernalia and left the premises immediately because of the related health and safety concerns. Malcolm was told by the local authority that, before the remainder of the work could be completed, his house would have to be 'made safe' by environmental health. In the meantime, he was left without a working toilet and had had to rely on the kindness of his neighbours letting him use their facilities.

This had been going on for over a year - environmental health inspectors visited the property on numerous occasions and found no drug paraphernalia and therefore no work that needed to be done to make it safe. However, despite Malcolm's repeated requests, the original repairs were not completed.

Malcolm met with an independent advocate, who spent some time with him outlining his various options and getting to know the situation. Malcolm expressed a desire to contact the local authority again, this time with independent advocacy support, so he and the independent advocate called their offices. Malcolm observed that, on this occasion, he was treated much more respectfully by the local authority and the issue was handled in a totally different way. The person he was speaking to took time to explain the relevant processes, looked in to what might be going wrong and took the necessary actions to set things right.

As a direct result of the phone call, local authority workmen were sent to Malcom's house within the week. They completed the repairs, thus restoring his dignity and materially improving his living conditions.

### This case study illustrates the following Standards:

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.

- Indicator 1: Enable your advocacy partner or advocacy group to understand their rights, and ensure that they are recognised by others.
- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- Indicator 15: Ask decision makers to explain why an action is taken where required.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.

# Case study 16 – Non-instructed advocacy supporting a young autistic man transitioning into adult care services

Younis was a young man with autism and Obsessive Compulsive Disorder (OCD) who had been given notice that his current school placement was due to end when he turned 18. His parents were not happy with the way the transition was being dealt with and made a referral to independent advocacy on their son's behalf. Because of Younis's very limited communication, he was supported according to the principles of non-instructed advocacy.

Younis was a young man with autism and OCD, who attended a residential school where he received two-to-one support. He had been given notice that this placement was due to come to an end as the school only supports people up to the age of 18. Younis's mother, who is also his Guardian, alongside Younis's father, contacted an independent advocacy organisation to make a referral on Younis's behalf.

Younis's OCD manifested in carrying out rituals around his placement. He had very sensitive sensory reactions and had historically become agitated and aggressive on occasion, although these behaviours had improved since he started attending the residential school.

The local authority had not offered an alternative care placement and had advised Younis's parents that there was no adult service within the local authority that provided the same level of support. Consequently, Younis's mum was concerned that the alternatives would be either a

placement within the local authority with less support (Younis had previously attended a special needs school that had proved unsuitable as he could not cope in the environment and the staff could not cope with his behaviour) or a placement with similar support outside the local authority (which would mean disrupting Younis's existing pattern of visiting home once a week and staying over at weekends). It was also not clear if Younis's current local authority would fund a placement in a different local authority area.

Because of all the uncertainty, Younis's parents wanted him to stay at the school for a further year and had requested the local authority to commit to this.

Younis's parents felt that the transition was being very badly managed and that he was being treated unfairly by the local authority. Consequently, they thought that he would benefit from the support of an independent advocate. Because of Younis's limited communication, the independent advocate supported him according to the principles of non-instructed advocacy.

The independent advocate supported Younis over the next year, including meeting with him in both his home and school environments to get a full understanding of how he interacted and communicated. The independent advocate also met with his parents and staff at the residential school a number of times and arranged critical meetings with social work and all relevant bodies to drive things forward.

Most recently, Younis and his parents had visited a service elsewhere in Scotland to allow staff to meet him and assess whether or not it would be a suitable placement. The service needed confirmation from Younis's local authority that they would fund the place, but his parents could not get a response from the allocated social worker. The independent advocate advised them to contact a senior social worker to highlight that the lack of correspondence was stalling the process and the situation remained unresolved. The independent advocate will pursue this.

This case study illustrates the following Standards:

- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.

- Indicator 2: Ensure your work promotes equality and challenges discrimination.
- Indicator 4. Identify and challenge any attitudinal, structural or environmental barriers to accessing, using or taking part in independent advocacy.
- Indicator 11. When advocating in a non-instructed context, make significant efforts to determine the rights, will and preferences of your advocacy partner, and where this is not genuinely practicable then make certain that decisions are taken with due consideration for their unique preferences, rights and perspectives.
- Indicator 15: Ask decision makers to explain why an action is taken where required.

## Case study 17 – Collective advocacy in a mental health hospital setting

An outline of how a long running collective advocacy group is facilitated and developed to have a collective voice. In the group, particular emphasis is placed on choice, flexibility and regularly reviewing how the group works.

A hospital providing acute and rehab psychiatric and mental health services has been the location for an independent patients' council running collective advocacy groups for 30 years. Taking place on each ward on a monthly basis, topics discussed at the collective advocacy groups can be practical ones to do with hospital facilities (e.g. the temperature on the ward), or staffing-related issues (e.g. cover for staff absences) or the provision of activities (e.g. gardening). Typically, there are clusters of common issues which emerge from different wards and these can then be taken forward. The group also acts as a forum for positive opinions to be expressed and fed back to hospital staff.

The collective advocacy groups are not chaired but facilitated, with the agenda set on each occasion by the group itself. Sometimes, there are external requests for specific issues to be covered, but these are only accommodated if they fit with an agenda item chosen by the group. In other words, the group develops an agenda that is 'bottom-up' rather than 'top-down'. The group also chooses the preferred location for each meeting, opting for a more private or more public space as required. Flexibility around agenda-setting and meeting locations demonstrates how the groups are open to regularly reviewing their preferred ways of operating.

Within the collective advocacy group meetings, people are encouraged and supported to contribute their views and experiences. However, it is made clear that the groups offer a confidential setting in which the

names of group members are not recorded, and any decisions or outcomes are described as "from the group". A volunteer with personal experience of mental health issues is always present, and they may draw on this to stimulate conversation. Coupled with asking direct open questions such as, 'what's life like on the ward at the moment?', this provides conversational ways for issues to be raised. In addition, the facilitator may make observations, picking up on interactions or comments people make. They check if the group wants to pursue topics and if they are indicative of wider, more systemic issues.

Once discussed and agreed on, issues are taken forward from the group via a range of channels, including immediate feedback to ward staff and various well-established groups including staff involved in hospital-wide decision-making. Any actions or impacts resulting from the work of the collective advocacy groups are fed back to members at future meetings. This has resulted in a number of positive changes to policy and practice over the years, including successfully campaigning to have secure lockers in which patients can keep personal items, developing hospital information materials and working with student mental health nurses to deliver training from the patient's perspective.

In addition, the collective voice of patients has had a wider influence beyond the hospital environment, as the patients' council has also played a part in speaking up about human rights issues, ultimately contributing to changes in policy at a local level. For instance, it highlighted the importance of the United Nations Convention on the Rights of Persons with Disabilities and effectively acted as a human rights champion to ensure the convention is located at the heart of local strategies. Members of the groups have been empowered to take on a useful role in civic society, by debating, discussing, and expressing opinion which has resulted in systemic structural change.

This case study illustrates the following Standards:

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.
- Standard 3c: Independent advocacy challenges discrimination and promotes equality and human rights.

- Indicator 1: Enable your advocacy partner or advocacy group to understand their rights, and ensure that they are recognised by others.
- Indicator 4: Identify and challenge any attitudinal, structural or environmental barriers to accessing, using or taking part in independent advocacy.
- Indicator 8: Uphold the confidentiality of your advocacy partner in line with the organisation's confidentiality policy including being honest when the policy should be breached.
- Indicator 13: Practice and promote effective communication with your advocacy partner or advocacy group, especially when they may face barriers.
- Indicator 16: Ensure that you seek and are guided by feedback from your advocacy partner or advocacy group members.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.
- Indicator 18: Make every effort to enable your advocacy partner or advocacy group members to have the opportunity to develop skills and confidence to advocate for themselves.

- Indicator 19: Make every effort to support an advocacy group to debate and reflect on the views and experiences of the group members as well as agreeing issues to take forward.
- Indicator 20: Enable advocacy group members to be open and regularly review the way the group works.
- Indicator 21: Support the advocacy group to define and agree the internal and external boundaries of confidentiality.

### Case study 18 – How collective advocacy might begin and evolve

An overview of the experiences of an independent advocacy organisation that facilitates a range of collective advocacy groups. Each group is focused on a different issue but they all share the same underlying principles and ways of working.

The independent advocacy organisation described the two different routes by which their collective advocacy groups are normally formed. Sometimes, independent advocacy groups are formed because people's views are being sought on a particular issue. For example, a group formed in relation to the relocation of a counselling service and then continued as a longer-term group representing the views of those with experience of trauma. At other times, a group can be initiated to ensure that the voice of a particular set of people is heard in order to raise awareness and influence policy and practice. For example, a group was developed building on people's experience of eating disorders to ensure that lived experience was captured and shared creatively with relevant professionals.

All collective advocacy groups need to make it very clear that the underpinning rationale for a collective advocacy group developing is for group members to effect change - a group might provide some support for those involved, but this is not its primary function.

It is important that each group is formed with ground rules or a group agreement, setting out what the group wants to work on and how they will do that. This may involve members reflecting on their unique views and experiences so they can then decide what actions they want to take forward collectively. Confidentiality is key, with members typically being encouraged to be open about themselves and their experiences, on the understanding that the information will stay within the group, (although anonymised experiences can then be talked about outside the group if appropriate).

For some groups, the focus is on reducing discrimination by increasing knowledge of a particular condition. For instance, a group focusing on psychosis has broken down barriers, increased awareness, and reduced prejudice by ensuring that the voices of those with first-hand experience are heard. Similarly, the members of the eating disorders group made a film to raise awareness of their experiences, which they took into schools as an educational resource, stimulating wider discussion on mental health and identity.

In some groups, despite the presence of a common theme, members may all have had very different experiences, creating less unity than might be expected. For example, a group for people with experience of trauma found that a high level of facilitation was required to establish appropriate levels of respect, understanding and freedom of speech to ensure tolerance between group members, whose personal stories could sometimes trigger others.

Groups often change over time in terms of the people involved, and so there is a need to regularly review the basis of the group's working practice. At other times, groups will evolve organically as their own understanding and sense of purpose evolves. For instance, in the case of the group, they focused on experiences of trauma. The growing profile of the concept of 'Adverse Childhood Experiences' led members to take an interest in this area, relating it to their personal experiences and then moving in a new direction by contributing to trauma-informed practice of healthcare professionals.

Groups are supported by a facilitator, who can seek information, highlight possible opportunities, and support a group to move its desired actions forward, but it is always up to the group to choose its priorities and actions. For example, a group may want to have more of a voice strategically and nationally. The group facilitator can help the group to be informed and prepared before contributing to, for example, a cross party mental health group, channeling the group members' interest and enthusiasm, but with the contribution itself remaining that of the group.

Members of independent advocacy groups often create friendships, grow in confidence, learn new skills, and gain a sense of purpose. All this stems from people with particular experiences coming together for a shared purpose and being seen as equal contributors possessing valuable knowledge and experience.

This case study illustrates the following Standards:

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3c: Independent advocacy challenges discrimination and promotes equality and human rights.

- Indicator 2: Ensure your work promotes equality and challenges discrimination.
- Indicator 5: Address any power imbalance between yourself and your advocacy partner or the advocacy group, or within the group.
- Indicator 8: Uphold the confidentiality of your advocacy partner in line with the organisation's confidentiality policy including being honest when the policy should be breached.
- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- Indicator 14: Not take the side of anyone other than your advocacy partner or advocacy group or try to influence them on behalf of others.
- Indicator 18: Make every effort to enable your advocacy partner or advocacy group members to have the opportunity to develop skills and confidence to advocate for themselves.
- Indicator 19: Make every effort to support an advocacy group to debate and reflect on the views and experiences of the group members as well as agreeing issues to take forward.
- Indicator 20: Enable advocacy group members to be open and regularly review the way the group works.
- Indicator 21: Support the advocacy group to define and agree the internal and external boundaries of confidentiality.

# Case study 19 – A collective advocacy project initiated and steered by group members to look at mental health and experiences of A&E

A collective advocacy group secured funding to drive forward a specific piece of project work – which had been identified by group members as a priority - exploring the impact of people's mental health history on their experiences of A&E.

Sometimes, collective advocacy groups already in existence can initiate specific pieces of work to address issues that have arisen for group members. One such example comes from a collective advocacy group led by people with lived experience of a mental health problem or diagnosis.

Group members had shared their experiences of A&E services at two hospitals and found that various aspects of the A&E environment had been challenging for them. In some cases, A&E staff had perceived them differently once their mental health history was known, which had sometimes overshadowed diagnosis and negatively impacted on their treatment.

These common experiences then became the catalyst for the development of a project. Funding became available which made possible the recruitment and management of peer researchers to explore these issues further. However, first of all it was important to ensure that there was no conflict of interest and that the integrity of the group would be maintained. The values of the funding were found to be a good fit, and it was determined that the resulting work would contribute to collective advocacy, with the views and interests of

members remaining the primary driver for any action. Consequently, the 'A&E' project began.

With funding secured, a group of peer researchers was recruited to gather views from people with lived experience of mental health problems who had experienced A&E in hospital. They adapted an existing assessment tool to ensure it would make those participating in the research feel safe and most able to take part. Whilst this made the process longer, it also meant that the process was more likely to be accessible to people.

As the project developed, efforts were continually made to ensure that group members were comfortable with its direction and regularly offered the opportunity to be involved. The importance of understanding that a collective advocacy group is made up of individuals was always a consideration - members had the option to be involved flexibly, in different ways, taking part on their own terms. In this way, they felt safe and in control, rather than feeling overwhelmed by their involvement.

The release of the peer research results initiated an invitation from senior NHS staff to discuss the issues raised and steps that could be taken to improve people's experiences at A&E. This, in turn, led to specific positive actions, including group members taking part in training for NHS staff, and the development of an emergency card that people can choose to fill in and present at A&E. The card sets out information they want staff to be aware of and enables them to communicate more easily their wishes at a time of potential stress.

Over the course of this piece of work, the collective advocacy group raised issues, identified common themes, initiated a project, collected and represented experiences, broke down barriers and, ultimately, made positive changes in order to address the problems they had experienced.

This case study illustrates the following Standards:

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3c: Independent advocacy challenges discrimination and promotes equality and human rights.

- Indicator 2: Ensure your work promotes equality and challenges discrimination.
- Indicator 7: Look out for, declare and minimise conflicts of interest in line with the organisation's conflict of interest policy.
- Indicator 9: Act on the issues agreed by your advocacy partner or advocacy group at the appropriate pace.
- Indicator 16. Ensure that you seek and are guided by feedback from your advocacy partner or advocacy group members.
- Indicator 17. Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.
- Indicator 18. Make every effort to enable your advocacy partner or advocacy group members to have the opportunity to develop skills and confidence to advocate for themselves.
- Indicator 19: Make every effort to support an advocacy group to debate and reflect on the views and experiences of the group members as well as agreeing issues to take forward.
- Indicator 20: Enable advocacy group members to be open and regularly review the way the group works.
- Indicator 21: Support the advocacy group to define and agree the internal and external boundaries of confidentiality.

# Case study 20 – Independent advocacy and advice: distinct but complementary support services

Independent advocacy and advice provision are distinct but complementary services that can work in concert with one another to provide marginalised people with holistic and seamless support.

An advocacy organisation works closely with its local Citizens Advice Bureau (CAB) in jointly supporting individuals. Staff from both organisations have established good working relationships with each other, based on a clear understanding of the differing roles of advocacy and advice and the boundaries of workers providing these forms of support.

Advocacy staff see themselves as effectively offering a 'triage' approach. They have first point of contact when they can get to know an individual, making an assessment of the advice that person might need as well as the independent advocacy support which would help them communicate about their situation in order to access that advice. The independent advocacy organisation recognises that CAB staff have a far greater depth of knowledge about many of the issues - such as benefits or housing which commonly feature in the challenges people face.

After this initial contact, staff might, if relevant, suggest the option of accessing the CAB for advice. The independent advocate can assist this contact as required, including accompanying the person to appointments and, if necessary, supporting them to communicate their situation or representing them.

"We know their background and context, so we are well-positioned to support them. We might know that they would find appointments or office environments intimidating, so we could support them appropriately to participate in a process they might otherwise find challenging. Or we might know about particular communication issues for example, someone on the autistic spectrum or with learning disabilities who would struggle to express or explain their situation. It's about the right support at the right time. Going with them to meet with a CAB adviser means that they have someone to help them access that process more easily. Responding to feedback from people as we go, we sometimes find that they have gained sufficient confidence to continue

Assure staff have found that working in this way means that independent advocacy and CAB workers are enabled to do their jobs in the most effective way possible, with both organisations 'working in tandem'. "Our role [as an independent advocacy organisation] begins by listening to people, understanding their situations and their capacity, and looking for triggers that suggest what the next level of support or advice would best be for them. We know a certain amount of information which leads us to suggest that their next step might be contact with a particular organisation. We then support them to do that and to engage in whatever process is involved."

The collaborative working between the advocacy staff and the local CAB now extends to the organisations sharing training on topics of relevance to all staff, such as resilience. This highlights that, while independent advocates and CAB advisers have distinct roles, they share some common experiences.

This case study illustrates the following Standards:

with less support from an independent advocate."

 Standard 1c: Independent advocacy provides no other services, has no other interests, ties or links other than the delivery, promotion, support and defence of independent advocacy.

- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.
- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.

- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- Indicator 13: Practice and promote effective communication with your advocacy partner or advocacy group, especially when they may face barriers.
- Indicator 14: Not take the side of anyone other than your advocacy partner or advocacy group or try to influence them on behalf of others.
- Indicator 16: Ensure that you seek and are guided by feedback from your advocacy partner or advocacy group members.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.
- Indicator 18: Make every effort to enable your advocacy partner or advocacy group members to have the opportunity to develop skills and confidence to advocate for themselves.

# Case study 21 - Independent advocacy with a teenager attending child protection meetings

Molly was a 13-year-old girl with epilepsy and physical disabilities. She was no longer able to live with her parents and had been referred to an independent advocacy organisation for support with child protection meetings.

Molly was a 13-year old girl who was living with her grandmother, as she could no longer live with her mum and dad due to their drug misuse. She was finding it hard to express her views and preferences during child protection meetings and was referred to independent advocacy by a social worker.

The independent advocate met with Molly on numerous occasions, tailoring these meetings to Molly's ability and communication needs. She used tailored signing when talking to Molly to find out how she was feeling, and what she wanted. The independent advocate also used pictures and Talking Mats to find out about the people in Molly's life and her likes and hobbies. This enabled the independent advocate to establish Molly's views – some of which her family and other professionals were not aware of.

The independent advocate liaised with key professionals, including social workers and Molly's school, to find out about upcoming child protection meetings and establish the best times to meet with Molly. Effective communication with other professionals helped ensure that Molly's views were included in the meetings regarding her care.

Molly's independent advocate explained the child protection meetings

and attended them with her, making sure that Molly's opinions and preferences were shared. Following the meetings, the independent advocate helped Molly to understand the decisions and the reasons they had been made.

Molly told her independent advocate things that she had felt unable to tell her family out of fear of upsetting them. For example, Molly explained that she was keen to move back in with her mum and dad, but was worried about telling anyone this as she did not want to upset her gran. Molly and her independent advocate talked about why she wanted to return home and what she missed at her mum and dad's. The independent advocate also helped explain the reasons why social workers had decided it was best that she lived with her gran for the time being.

With Molly's permission, the independent advocate shared her views with social work and her parents, enabling them to tailor contact and family time together to include things Molly wanted to do. For instance, Molly wanted to see her pets and spend more time with her aunt and cousins.

Molly was much happier - she felt like she was being listened to and that her opinions were important, and she was able to carry on having fulfilling relationships with her parents and extended family, while still living with her gran.

This case study illustrates the following Standards:

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.

- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.

- Indicator 4: Identify and challenge any attitudinal, structural or environmental barriers to accessing, using or taking part in independent advocacy.
- Indicator 8: Uphold the confidentiality of your advocacy partner in line with the organisation's confidentiality policy including being honest when the policy should be breached.
- Indicator 12: Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- Indicator 13: Practice and promote effective communication with your advocacy partner or advocacy group, especially when they may face barriers.
- Indicator 16: Ensure that you seek and are guided by feedback from your advocacy partner or advocacy group members.
- Indicator 17: Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.

### Appendix 1 – Principles, Standards and **Indicators**

### The three principles which underpin all independent advocacy work:

- Principle 1: Independent advocacy is loyal to the people it supports and stands by their views and wishes.
- Principle 2: Independent advocacy ensures people's voices are listened to and their views taken into account.
- Principle 3: Independent advocacy stands up to injustice, discrimination and disempowerment.

### The eight standards, which slot under the principles and provide additional context and detail:

Standards that underpin Principle 1 (Independent advocacy is loyal to the people it supports and stands by their views and wishes):

- Standard 1a: Independent advocacy follows the agenda of the people supported regardless of the views, interests and agendas of others.
- Standard 1b: Independent advocacy must be able to evidence and demonstrate its structural, financial and psychological independence from others.
- Standard 1c: Independent advocacy provides no other services, has no other interests, ties or links other than the delivery, promotion, support and defence of independent advocacy.

Standards that underpin Principle 2 (Independent advocacy ensures people's voices are listened to and their views are taken into account):

- Standard 2a: Independent advocacy recognises and safeguards everyone's right to be heard.
- Standard 2b: Independent advocacy reduces the barriers people face in having their voice heard because of communication, or capacity, or the political, social, economic and personal interests of others.

Standards that underpin Principle 3 (Independent advocacy stands up to injustice, discrimination and disempowerment):

- Standard 3a: Independent advocacy recognises power imbalances or barriers people face and takes steps to address these.
- Standard 3b: Independent advocacy enables people to have more agency, greater control and influence.
- Standard 3c: Independent advocacy challenges discrimination and promotes equality and human rights.

#### The 21 indicators for independent advocates:

- 1. Enable your advocacy partner or advocacy group to understand their rights, and ensure that they are recognised by others.
- 2. Ensure your work promotes equality and challenges discrimination.
- 3. Reflect on your practice and be aware of your own opinions, prejudices and discriminatory views and values and not let them affect your practice.
- 4. Identify and challenge any attitudinal, structural or environmental barriers to accessing, using or taking part in independent advocacy.
- 5. Address any power imbalance between yourself and your advocacy partner or the advocacy group, or within the group.
- 6. Not withhold information from your advocacy partner.
- 7. Look out for, declare and minimise conflicts of interest in line with the organisation's conflict of interest policy.
- 8. Uphold the confidentiality of your advocacy partner in line with the organisation's confidentiality policy including being honest when the policy should be breached.
- 9. Act on the issues agreed by your advocacy partner or advocacy group at the appropriate pace.
- 10. Enable your advocacy partner or advocacy group to outline, record and review their expectations.
- 11. When advocating in a non-instructed context, make significant efforts to determine the rights, will and preferences of your advocacy partner, and where this is not genuinely practicable then make certain that decisions are taken with due consideration for their unique preferences, rights and perspectives.

- 12. Support your advocacy partner or advocacy group to gain information, understand options and explore possible outcomes.
- 13. Practice and promote effective communication with your advocacy partner or advocacy group, especially when they may face barriers.
- 14. Not take the side of anyone other than your advocacy partner or advocacy group or try to influence them on behalf of others.
- 15. Ask decision makers to explain why an action is taken where required.
- 16. Ensure that you seek and are guided by feedback from your advocacy partner or advocacy group members.
- 17. Support your advocacy partners or advocacy group members to gain more control and influence in the decisions and circumstances that affect their lives.
- 18. Make every effort to enable your advocacy partner or advocacy group members to have the opportunity to develop skills and confidence to advocate for themselves.

### In addition, the following indicators apply only to collective advocacy:

- 19. Make every effort to support an advocacy group to debate and reflect on the views and experiences of the group members as well as agreeing issues to take forward.
- 20. Enable advocacy group members to be open and regularly review the way the group works.
- 21. Support the advocacy group to define and agree the internal and external boundaries of confidentiality.

Note, in addition to the 21 indicators for independent advocates, there are 23 indicators for independent advocacy organisations. These can be found on pages 24-25 of the 'Principles, Standards and Code of Best Practice'. We have not included them here as they have a more operational focus and the case studies do not reference them.

Scottish Independent Advocacy Alliance <u>www.siaa.org.uk</u>

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