

Litigating the right to community living for people with mental disabilities

A handbook for lawyers

# Litigating the right to community living for people with mental disabilities

A handbook for lawyers





September 2014

Copyright statement: © Mental Disability Advocacy Center (MDAC), 2014. All rights reserved.

ISBN 978-615-80107-2-6

Supported [in part] by a grant from the Open Society Foundations.

The picture on the front page is of MDAC client Boganka Harayama who lives in Bulgaria. © MDAC.

#### **Contents**

1.	Summary	5
2.	Context and aim	7
	2(A). Context	
	2(B). Aim and outline	
	Acknowledgments	
3	Using strategic litigation to secure the right to live in the community	10
٠.	3(A). What is strategic litigation?	
	3(B). Purpose and objectives of strategic litigation.	
	3(C). Making litigation strategic	
	3(D). After the judgment	
	3(E). MDAC's contribution	
4.	Arguments and scenarios	15
	4(A). The right to live in the community	
	4(B). Arguments pool	
	4(B)(i). Community support services	
	4(B)(ii). Liberty	
	4(B)(iii). Privacy, family and home	
	4(B)(iv). Non-discrimination	
	4(B)(v). Access to justice	
	4(B)(vi). Fair trial	
	4(B)(vii). Institutional conditions	21
	4(C). Scenarios.	
	4(C)(i). Anna lives in an institution and wants to get out	24
	4(C)(ii). Boris faces retribution	24
	4(C)(iii). Charles lives in an institution with appalling conditions	
	4(C)(iv). Dora lives in the community but is denied support services	25
	4(C)(v). Erik is a child who goes to special schools but who faces adulthood with no services	26
5.	Practicalities of litigating the right to live in the community	28
	5(A). How can I represent someone who has been deprived of their legal capacity?	
	5(B). How do I receive instructions and evidence from my client if she/he is denied access to the outside world?	
	5(C). What should I do if my client is being harmed?	32
	5(D). What should I do if I doubt my client can live independently in the community?	34
	5(E). How can I get my client community-based services so that they can leave the institution?	
	5(F). My client has "litigation fatigue". What should I do?	36
Αŗ	pendix 1. Case law	38
	European Court of Human Rights	38
	UN Committee on the Elimination of All Forms of Discrimination against Women	38
	Inter-American Court of Human Rights	38
Αŗ	pendix 2. Further Reading	39
	The right to community living	39
	Stratogic litigation	30



"I believe that law is a very good tool for change: the combination of strategic litigation, advocacy activities and raising awareness has proved that"

Maroš Matiaško Lawyer and MDAC Legal Monitor



This handbook is a practical tool for lawyers in Europe who wish to help clients with mental disabilities leave institutions so that they can live with supports in the community. The process of "deinstitutionalisation" is not simply a good thing to do, but an obligation on governments. The right to independent living in the community is just that – a human right, guaranteed by international law.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was adopted in 2006 and establishes that everyone has the right to choose where and with whom they live on an equal basis with others. Article 19 of the CRPD goes further, requiring that governments also provide disability-specific services, and obliging them to ensure the accessibility of general public services to all people with disabilities.

People with mental disabilities

By 'people with mental disabilities', MDAC means people with intellectual, developmental, cognitive, and/or psycho-social disabilities.

People with intellectual disabilities generally have greater difficulty than most people with intellectual and adaptive functioning due to a long-term condition that is present at birth or before the age of eighteen. Developmental disability includes intellectual disability, and also people identified as having developmental challenges including cerebral palsy, autism spectrum disorder and fetal alcohol spectrum disorder. Cognitive disability refers to difficulties with learning and processing information and can be associated with acquired brain injury, stroke and dementias including Alzheimer's disease.

People with psycho-social disabilities are those who experience mental health issues or mental illness, and/or who identify as mental health consumers, users of mental health services, survivors of psychiatry, or mad.

These are not mutually exclusive groups. People with intellectual, developmental or cognitive disabilities may also identify, or be identified as, having psycho-social disabilities, or vice versa.

Whilst this handbook has primarily been written to address the rights of people with mental disabilities, the contents may also be useful for people with other disabilities too, including those with physical, sensory or multiple impairments.

The right to independent living in the community, like all others, is enforceable. This means that the legal systems of countries which have ratified the CRPD must ensure that people with disabilities can seek redress and legal remedies where they have been denied this right. Yet, the right to independent living in the community is multi-faceted, and requires legal representatives to take a comprehensive and holistic rights-based approach.

Where a person with a disability is forced to live in an institution, one of the key remedies will be to get them out of the institution so that they can live in the community. If a person is under guardianship, which prevents them from making legally valid decisions about their lives, the remedy sought might be to remove the guardianship. And if the person has suffered abuse, violence or exploitation, the remedies might be compensation and an order for rehabilitation.

Despite the complexities, legal action and issuing court proceedings for clients with mental disabilities can be successful and have a transformative effect on their lives. Invariably, successful cases need a team of smart lawyers who argue effectively using the law and the facts. This handbook provides a number of potentially powerful legal arguments which can be employed to secure for people with mental disabilities the right to live in the community.

Reflecting the variety of situations which clients may need assistance with, this handbook provides argumentation on community support services, liberty, privacy, integrity and dignity, non-discrimination, access to justice and fair trial. The arguments can be used in a number of ways, including securing a clients' release from an institution, gaining services required to enable them to live independently, or where parents of a child with disabilities are wondering what will happen when their child turns eighteen and there are no adult services.

Many cases will present numerous practical hurdles which require careful strategising on the part of legal representatives. These include how to represent someone under guardianship when the domestic law does not allow them to instruct a lawyer directly; how to get instructions from a client who is inside an institution and barred from accessing the outside world; how to protect a client who is being harmed or at risk of retaliation; how to get in place supports so that the client can actually live outside an institution; and how to support the client successfully to avoid them feeling 'litigation fatigue' and from withdrawing their legal claims.

Lawyers who wish to discuss case strategies should contact MDAC's litigation team via <a href="www.mdac.org">www.mdac.org</a> or by email <a href="mailto:support@mdac.org">support@mdac.org</a>.



"The core of the right [to live in the community], which is not covered by the sum of the other rights, is about neutralizing the devastating isolation and loss of control over one's life"

Thomas Hammarberg

Former Council of Europe Commissioner for Human Rights, MDAC Honorary President

## 2. Context and aim

#### 2(A). Context

An estimated 2 million people with mental disabilities are held, against their will, in institutions across the Council of Europe region alone. These people are denied a right that many people take for granted – namely, the right to choose where and with whom we live – and they are denied alternative forms of accommodation. They are subjected to a wide range of abuse, exploitation, and violence inside long-term institutions, become invisible in the public domain, and are a low priority for many governments.

Top-down advocacy by intergovernmental organisations has brought successes in some countries, drastically reducing the number of beds in psychiatric hospitals. It has also been successful in establishing the right to live in the community in international law and rhetoric. But the numbers of residents in long-stay social care institutions have remained stagnant, with very few good practice examples to speak of. Monitoring in the Czech Republic, for example, suggests that the process of closing social care institutions was so badly managed that people with intellectual disabilities ended up being placed in psychiatric institutions. <sup>1</sup> This is because the government is simply paying lip-service to the right to live in the community.

Bottom-up grassroots initiatives run by small NGOs have had an effect in demonstrating that alternatives to institutions are viable, but no government has scaled up these pilot projects. Instead, services continue to be largely centralised in large or small institutions, rather than in the community. Segregation is posed as 'therapy' and 'care', and governments use euphemisms such as "group homes" and "living centres" to avoid being accused of the truth: that they are building new institutions which will segregate future generations of people with mental disabilities. Paternalism pervades many government policies, seeking to legitimise proxy decision-making on behalf of people with mental disabilities with reference to their "best interests" (subjecting them to institutionalisation) rather than respecting their will and preferences (to live in the community).

Tens of millions of Euros in EU structural funding are used by governments in contemporary Europe to maintain, renovate and even build new institutions. This means that European taxpayers' money is being used to fund systemic human rights violations, denying many people with disabilities the opportunity of gaining their independence. Political decisions in Brussels have

financed a decrepit and abusive system of institutionalisation, rather than investing in inclusion and community development. MDAC uses litigation to challenge these discriminatory funding policies and secure restitution to the thousands of people affected.

Most governments have not yet enacted the laws and policies necessary for securing safe and inclusive communities for people with mental disabilities. Large, abusive institutions are still the norm in much of Europe and beyond. Mental health and social care professionals, as well as local communities, lobby strongly to maintain the status quo because of the financial benefits to them and the fear of change.

Stigma against people with mental disabilities remains pervasive. Many governments lack the long-range vision it takes to initiate reform, and policy-makers lack the expertise to shift budgets, monitor benchmarks and involve civil society. The media is often against the notion that people with mental disabilities should live in our communities, and governments rarely respond to the popular press with arguments grounded in human rights. It falls then to civil society to play a watchdog role, hold States to account, and promote inclusion.

Courts have only in the past few years started to get to grips with the fact that people with mental disabilities are subjected to abuse and neglect as a result of institutionalisation, and that ill-treatment should not be part of a mental health treatment package. Courts can play a key role in implementing the right to live in the community, by ordering local governments to put in place community support services which prevent institutionalisation. They can also play a part in finding that domestic law fails to give effect to international standards and, by doing so, compel governments to take action.

MDAC recognises that courts need information and 'good cases' (good facts, with good evidence) to enable them to issue judgments which advance rights. The role of the lawyer in preparing and conducting high quality litigation is essential in supplying this need. MDAC is a small organisation that plays a convening and support role in litigation internationally. Local lawyers are urgently needed to assist in bringing the cases to domestic courts and creating a global impetus towards the realisation of the right to live in the community.

<sup>1</sup> Mental Disability Advocacy Center, Cage beds and coercion in Czech psychiatric institutions, (Budapest: MDAC, 2014), 23.

#### 2(B). Aim and outline

MDAC's vision is a world of equality – where emotional, mental and learning differences are valued equally; where the inherent autonomy and dignity of each person is fully respected; and where human rights are realised for all persons without discrimination of any form.

Within its "My Home, My Choice" campaign, MDAC's goal is that people with mental disabilities are enabled to participate fully in our communities, where they are safe and supported to live in homes that they choose. This means that institutions should be closed, and that people responsible for segregation, torture and abuse are held to account.

This handbook is for lawyers who want to use the law to help advance the right to live in the community for people with mental disabilities. It provides lawyers with tools to bring legal challenges against institutionalisation (often long-term), segregation and isolation, and to call for community support services.

MDAC has developed this handbook to consolidate and share its learning about how strategic litigation can be used as a tool to advance these rights. Litigation in this area addresses a complex set of connected rights, and often MDAC asks courts to interpret obligations under the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). The CRPD has become a vital tool in successfully securing the right to community living through the courts, particularly in countries where domestic law fails to guarantee the relevant rights, or where there are no legal precedents to guide the courts.

This handbook is written with the particular experience of lawyers in Europe in mind. It draws on the CRPD, and also on the European Convention on Human Rights (ECHR). Specific challenges are present in each jurisdiction, requiring a high degree of flexibility and creativity from legal representatives. Whilst the contents of this handbook address European jurisdictions, it is hoped that it may also be of interest further afield.

As with all human rights litigation, lawyers must tailor strategies to the concrete contexts in which the violations of the right take place, and nuances of differing systems in specific courts or tribunals. This handbook does not suggest a "one size fits all" model for conducting litigation, nor does it seek to provide solutions to the multiplicity of challenges that may arise in this developing area of law. Instead, the intention is to provide a framework which can support creative lawyers to prepare for and successfully litigate the right to community living on behalf of clients who may be in particularly vulnerable or precarious positions.

This chapter situates the right to community living as a key development of international law seeking to redress a history of mass-institutionalisation and exclusion suffered by millions of people with disabilities, a situation which continues in much of Europe today. Chapter 3 sets out the purpose of strategic litigation, and offers practical tips about initiating litigation in this area, and what to do after judgment. It also describes how MDAC can help lawyers around the world to take such cases.

Chapter 4 presents some of the main arguments which lawyers can deploy in the courtroom to advance the right to live in the community. To show the concrete application of these arguments, five hypotheticals are set out – typical case scenarios – and the arguments are applied to each of them. Chapter 5 examines the practicalities of this type of litigation, providing a number of strategies to employ during the court process to overcome some of the barriers that can arise. These are based on practical questions and problems faced by lawyers working with MDAC over a number of years.

#### **Acknowledgments**

MDAC conveys its thanks to the following people for contributing expertise, information and ideas which made this handbook possible.

Aneta Genova, Lawyer and MDAC Legal Monitor, Bulgaria Aleksandra Ivanković-Tamamović, external advisor Maroš Matiaško, Lawyer and MDAC Legal Monitor, Czech Republic

Barbara Méhes, MDAC Legal Officer

Katherine Morley, MDAC Project Manager Lycette Nelson, former MDAC Litigation Director Ádám Szklenár, MDAC Digital Media and Communications Assistant

Paige Casaly and Frances McCormack, MDAC interns

**Ann Campbell**, MDAC Litigation Director, is the primary author of the handbook. **Steven Allen**, MDAC Advocacy and Communications Director, and **Oliver Lewis**, MDAC Executive Director, assisted with structure and editing.



"This decision is extremely important in Romania and also across Europe. [...] The decision sets a precedent that will help tens of thousands of people in similar situations to Valentin Câmpeanu across the continent."

Georgiana Pascu

Program Manager

Center for Legal Resources (Bucharest) on the significance of the ECHR judgment in Valentin Câmpeanu v Romania



## Using strategic litigation to secure the right to live in the community

#### 3(A). What is strategic litigation?

Strategic litigation is a method that can bring about significant changes in the law, practice or public awareness through taking carefully-selected cases to court. The clients involved in strategic human rights litigation have been victims of rights abuses that are suffered by many other people. In this way, the strategic element of such litigation focuses on an individual case in order to bring about broader, systemic change.

Progress can be made on the right to live in the community via strategic litigation. However, litigation cannot operate in isolation. Strategic impact is significantly more likely when litigation operates as part of a broader set of activities including policy advocacy, capacity-building of NGOs, and public awareness campaigns. Together, these tools can comprehensively tackle a specific issue through a multifaceted approach. Litigation can be a source of remedies and ensure that case law at the national level is informed by international human rights standards. It can be used in both common law systems, where judge-made law is much more common, and in civil law jurisdictions, where it can play a persuasive and interpretive role.

#### 3(B). Purpose and objectives of strategic litigation

Objectives of strategic litigation may include:

- Creating progressive jurisprudence which advances human rights;
- 2. Instigating reform of domestic laws which do not comply with international human rights laws;
- 3. Ensuring that laws are interpreted and enforced properly;
- 4. Documenting human rights violations;
- 5. Empowering people with disabilities who have been victims of human rights abuses and rebalancing historic injustices.

Strategic litigation can be used to develop legal standards and judicial practice at the national and international levels, or where law reform is already underway or proposed. It can also give content and scope to legal obligations which are underdeveloped at both the national and international levels. It is particularly useful in focusing awareness on issues faced by people without a strong voice in society, where their concerns fail to reach the policy table and are ignored by the media. Frequently, the concerns of people with mental disabilities are ascribed a low priority by decision-makers. Strategic litigation can be used to drive them to take action.

#### 3(C). Making litigation strategic

Ensuring the strategic impact of litigation requires planning at each stage of case management, namely:

- 1. Preparation,
- 2. Conduct, and
- 3. Post-decision implementation.

In the preparation phase, lawyers should identify a clear objective for the litigation and situate this objective within

a wider national, regional and/or international legal and social context. For example, a national law may not contain a justiciable right to live in the community for people with disabilities, but if there is no national impetus for change among domestic civil society, it may not be appropriate to choose to litigate the issue immediately. Instead, it may be more effective to litigate particular elements of this right, for example access to specific services. That said, much will depend on the local context, and there is often no single correct approach.

In determining which cases are likely to achieve a strategic impact, lawyers should work closely with civil society organisations to identify their primary concerns. A partnership could be a long-term cooperation throughout the course of litigation. This cooperation can strongly influence the successfulness or otherwise in achieving the objectives of litigation and should be used to develop a comprehensive approach, as well as drawing on a broad range of resources to support the strategy.

To achieve strategic impact, the issues that are chosen for litigation must represent broader, systemic problems or a failure to implement specific human rights provisions. A number of factors can be considered, including:

- Estimates of the numbers of people experiencing similar human rights violations who might benefit from a judicial remedy being established;
- The instrumental value of certain claims in achieving broader reform (e.g. litigating the right to access court directly as a way for people with disabilities to challenge their placement under guardianship);
- The potential for the judiciary to establish positive obligations on government entities to protect or fulfil certain rights (e.g. the obligation to provide individualised services);
- The existence of promising alternatives which can be used to persuade judges of the feasibility of granting a remedy (e.g. in-home support services to enable people with disabilities to live independently);
- Legislative or policy reforms that fail to implement human rights standards, and where positive judicial determinations may have an impact.

Once the issue has been defined within a larger context, the lawyer must determine whether the facts presented by a particular client are likely to support the objectives of strategic litigation. In many cases, it may be that litigation will have a beneficial impact for the person concerned, but nevertheless fails to support the strategic objectives. In these cases, it is important that lawyers have a clear plan about whether they take on such clients, or refer them elsewhere.

As with any client, it is important for the lawyer to assess the likely impact of litigation on them. This is even more important in cases seeking a strategic impact. Lawyers should ensure the client is aware of the broader context and that their case will contribute to a broader strategy, so that they can give free and informed consent to this. It is essential to assess and mitigate any risks of undertaking litigation on behalf of the client, in close cooperation with them and with NGOs.

Client care and planning for non-legal support are likely to have a significant bearing on the outcome of litigation. When litigating the right to live in the community, the lawyer will be representing a person who is likely to be vulnerable to exploitation or abuse, and who has been without support for some time. Whilst it is not the lawyer's job to provide numerous non-legal supports to their client, it is important that they can

provide clients with information on accessing a variety of supports they may need, bearing in mind their specific disability-related needs and the predictable effects of litigation which may take several years. Aspects of the client's identity such as their gender, age, health status, race etc. may give rise to different challenges in this regard which must be separately identified and addressed.<sup>2</sup>

Once the client care issues are in place, lawyers can consider the appropriate forum for bringing litigation. This may be a local court, an appeal court, an equality body, a constitutional court, and so on. It may be an international court or tribunal, or a UN treaty body. The choice will depend on the facts of the case and the legal system. Each forum will have advantages and drawbacks in meeting the objectives of strategic litigation. Prompt questions which the lawyer may find useful to answer include:

- 1. How long will the tribunal/court take to reach a final determination? This can have a serious effect both on the client and on the financial sustainability of the litigation.
- 2. Can the tribunal/court hear testimony from the victim or witnesses? What forms of evidence do they accept? Have they heard any cases from people with mental disabilities before? What prejudices might the judges have? What can the lawyer do to ensure that judges do not dismiss evidence from their client as lacking credibility?
- 3. What remedies are available? The lawyer should be as specific as possible in requests for relief and be sure to identify the body which can grant the most appropriate remedy, both for the client, and with a view to the larger strategic objective.
- 4. Does the tribunal/court already have jurisprudence in this area? If not, might they be amenable to developing it? In these situations, it is important to assess the risk of a negative outcome if it is unclear how the particular tribunal/court may decide. A different tribunal/court may offer more chance of success if this involves building on pre-existing jurisprudence.
- 5. Does the tribunal/court have a friendly settlement procedure? Is this optional or mandatory and what are the consequences of engaging in such a procedure? For example, some settlement procedures prohibit any publicity around the final settlement which may have serious consequences for any planned advocacy strategy. Some govern only compensation, while more useful procedures allow space for the authorities to promise to change or properly implement the law.
- 6. Does the tribunal/court offer interim measures (a temporary solution) if the violations are on-going and where the client is at risk of irreparable harm, for example living in an institution where it is known that the staff beat the residents?
- 7. Is the judgment of the tribunal/court legally binding? On whom? How are judgments enforced? Is there a follow-up or monitoring mechanism attached to the judgment? Which NGOs are available to carry out post-litigation advocacy?

<sup>2</sup> For more information, see Chapter 5, below.

Lawyers should consider whether they have the required resources to properly conduct the litigation. Sometimes this means finances, and often it means people resources: NGO activists, legal advisors, and people to support the client. If resources are lacking, fundraising may be necessary.

At all stages, the lawyer should consider cooperating closely with NGOs or other members of civil society as they might

be able to provide non-legal support to the client, as well as insights on the conduct of the litigation. When working in partnership, roles should be clearly assigned to each participant based on their areas of expertise. These may include gathering evidence, conducting the litigation, undertaking national level policy advocacy, providing non-legal support to the client, managing media relations and so on.

#### 3(D). After the judgment

A positive judgment in a strategic case may result in immediate improvement of the situation both for the client and for others in similar situations. In most cases, however, governments are slow to implement changes. Following judgment, there will often be other types of work necessary to effectuate the objectives of the litigation. Policy and law reform advocacy are almost always necessary. A media strategy should be developed, as should other awareness-raising activities. The capacity of people who can use the judgment may need to be strengthened, whether through formal training courses, evening seminars, case summaries or internet-based resources.

Follow-up litigation can play a central role in implementing or executing the "final" judgment. This can secure remedies for others who now have a precedent, or a basis from which others can claim their rights and demand that authorities take action in conformity with the judgment. For example, an international court may find that the institutionalisation of the client is a breach of her rights and that the State is obliged to take measures to ensure her right to liberty and to home, family and private life. In these cases States often take a minimalist approach by simply discharging the client from the institution, but they fail to enact law reform or make budgetary or service adjustments which would be needed to properly implement

the judgment. Follow-up domestic litigation can focus on exposing the practicalities of how the State should implement the judgment and can pinpoint weaknesses of the State's plans to roll out services, highlighting geographic inconsistencies, slow speed of action or discriminatory policies.

While a positive judgment is always better (for morale as well as law), in the context of strategic litigation, even a negative decision can be viewed as a success if grounded in the bigger picture. A negative judgment can highlight how difficult it is in practice for an institutionalised client to get legal remedies. It can identify gaps in law that prevent victims of violations from accessing justice. These findings can then ground recommendations and calls for law reform as part of targeted advocacy efforts. They can be used to engage media and draw attention both to the issues, lack of available remedies, and - potentially - a stigmatising judicial approach. A negative judgment at the national level can be a step in exhausting domestic remedies, which allows the lawyer to then take the case to an international court. A good strategy therefore should prepare from the outset to plan for both a positive and negative judgment, and to make the most from whatever the courts throw at the lawyer and their client.

#### 3(E). MDAC's contribution

As an international NGO focused on the issues facing people with mental disabilities, MDAC has over 12 years of experience in conducting strategic litigation in this regard. MDAC is the only international NGO that focuses on strategic litigation for people with mental disabilities. We have found it effective to pool resources and work in teams to conduct strategic litigation.

MDAC has secured a number of notable victories at various national and international courts using strategic litigation.

Among other cases, MDAC co-represented the applicants in the cases of Shtukaturov v. Russia³ and Stanev v. Bulgaria⁴ before the European Court of Human Rights. MDAC has also submitted third-party interventions in cases before that Court, including in Kędzior v. Poland⁵ and Z.H. v. Hungary.⁶ In the case of Bureš v. Czech Republic, MDAC highlighted the link between detention and abuse.

<sup>3</sup> Shtukaturov v. Russia, Judgment of 27 March 2008, Application No. 44009/05.

<sup>4</sup> Stanev v. Bulgaria [GC], Judgment of 17 January 2012, Application No. 36760/06.

<sup>5</sup> Kędzior v. Poland, Judgment 16 October 2012, Application No. 45026/07.

<sup>6</sup> Z.H. v. Hungary, Judgment of 8 November 2012, Application No. 28973/11.

<sup>7</sup> Bureš v. Czech Republic, Judgment 18 October 2012, Application No. 37679/08.

Over the next three years MDAC will strengthen its networks and grow its own capacities to scale up the effect that it can have. MDAC staff work in teams with national lawyers and NGOs, international law firms and international legal experts in a variety of areas to ensure that each case in which it is involved is chosen on the basis of case selection criteria, forms

an integral part of a larger advocacy strategy and incorporates the highest standard of argumentation to secure the most effective implementation of human rights. MDAC coordinates its advocacy and litigation strategies and participates in coalitions, seeks to secure media attention at litigation milestones and ensures advocacy follow-up to judgments.





"I'm not an object, I'm a person. I need my freedom."

Rusi Stanev
before the hearing of the
Grand Chamber of the European Court of Human Rights

## 4. Arguments and scenarios

The right to live in the community is like the head of an octopus, and its tentacles stretch into several other areas of law and human rights. It is MDAC's experience that progress on one of these rights cannot be made without tackling related human rights violations. Cases on the right to live in the community are invariably innovative, as so few cases have yet been argued in the world, with even fewer being clearly based on human rights.

This chapter has two parts. The first sets out a pool of arguments which lawyers can deploy in the courtroom. The aim is to give lawyers an understanding of how the right to live in the community relates to other human rights provisions, particularly regarding the right to non-discrimination and the right to legal

capacity. The chapter sets out how lawyers should nimbly use relevant provisions of the UN Convention on the Rights of Persons with Disabilities (CRPD) and other human rights instruments such as the European Convention on Human Rights (ECHR), the European Social Charter (ESC) and other UN human rights treaties.

The second part of the chapter sets out five scenarios that reveal typical legal problems related to the right to community living, drawn from experience in Europe. Each scenario demonstrates how the arguments pool can be used to advance the client's rights.

#### 4(A). The right to live in the community

Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) sets out that each person, irrespective of their disability or level of impairment, has the right to live in the community. The right is no longer a political goal or a policy nicety; it is an enforceable human right. The CRPD is binding international law for all countries which have ratified it and can be relied upon in court in many domestic jurisdictions. Article 19 of the CRPD sets out governments' obligations as follows:

Living independently and being included in the community, Article 19, CRPD

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community:
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs

The obligation therefore is that States must take "effective and appropriate measures" (not just reasonable or inexpensive ones) to make sure that people with disabilities enjoy "full inclusion and participation in the community" (not just minimal or reasonable participation). To achieve this, Article 19 sets out three elements:

- Paragraph (a) requires that people with disabilities must be provided with a genuine choice about where and with whom they live on an equal basis with others. This reflects the provision in Article 12 of the Convention on the right to legal capacity, which is an issue explored in the arguments pool below.
- Paragraph (b) is the obligation on States to provide disability-specific support services, and as the text says, these services must be provided to "prevent isolation or segregation from the community". There are two aspects to this. Firstly, services must be provided to prevent people with disabilities from being segregated in institution. Secondly, these services must also prevent the isolation of people with disabilities who physically live in the community. The second limb refers to individualised services and could relate to the provision of transportation, for example, or in-home assistance.
- Paragraph (c) points out that general public services
  must be made available and accessible to people
  with disabilities. Examples of this include access to
  job placement services, mobile libraries, accessible
  transportation, healthcare and the provision of
  accessible information for people with intellectual
  disabilities and so on.

#### 4(B). Arguments pool

The arguments pool presents seven clusters of legal arguments which, in MDAC's experience, are the most appropriate for lawyers to use when advancing their client's right to live in the community. Deployment of the arguments will of course depend on a variety of factors including the specific facts of the case, domestic law, and on prevailing norms of judicial argumentation in different legal fora.

The first cluster relates to the provision of community support services, and the issue of 'progressive realisation' – particularly important as governments frequently raise this as a justification for their slow progress in rolling out the right to live in the community. Second, the right to liberty is presented, and thirdly, a cluster of rights connected with privacy, family and home are outlined, which are important concepts in many domestic legal frameworks. The fourth cluster relates to the right to non-discrimination, followed by the fifth on access to justice. The sixth cluster relates to the right to a fair trial before the seventh which deals with challenging conditions in institutions. When litigating the right to live in the community, lawyers will inevitably face hurdles based on restriction of their client's legal capacity, and this is an issue which is covered in many of the argument clusters.

#### 4(B)(i). Community support services

According to Article 19 of the CRPD, States have the obligation to ensure that people with mental disabilities have access to specialised services in the community and also have equal access to mainstream community-based services. In order to achieve full inclusion and participation of people with mental disabilities in the community, a wide range of individualised support services must be provided by the State. It is widely accepted that these services must be available/adequate, accessible, acceptable, and adaptable.<sup>8</sup>

- Availability requires functioning services in sufficient quantity which are adequate in amount and duration to ensure an adequate standard of living and adequate health care.
- Accessibility requires that services are accessible to everyone, especially the most vulnerable groups, in law and fact, and without discrimination. This involves considerations of coverage, eligibility, affordability and physical access, among other things.
- Acceptability requires that the form and substance of services are acceptable, e.g. relevant, culturally appropriate and of good quality.

 Adaptability requires services to be flexible so that they can adapt to the needs of changing societies and communities and respond to the needs of individuals within their diverse social and cultural settings.

Where the State or local government fails to provide community-based (housing and other support) services and the only realistic option for people with mental disabilities is to live in an institution, the State fundamentally violates the requirement of Article 19 on ensuring that they can live independently in the community.

A violation of Article 19 of the CRPD can also be claimed if the client was denied the opportunity to take an active part in establishing social services for themselves, treating them as a mere passive user of services. The claim for participation of people with mental disabilities in the development of services under Article 19 is supported by the overarching principle of participation under Article 3(c) of the CRPD, and the general obligation on the State to include people with disabilities in the development of policies to implement the provisions of the CRPD.

#### Progressive realisation

The development of community services is subject to "progressive realisation". Article 4(2) of the CRPD sets out the duty. It states that:

With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of [Convention] rights...

This means that governments do not need to immediately provide full rights to housing, health, education and employment (classic economic and social rights) to everyone the day after the country ratifies the relevant international treaty. It does, however, require that governments organise and manage their budgets so as to achieve economic, social and cultural rights to the maximum extent possible within available resources over a reasonable period of time. Governments must roll out these rights on the basis of the principle of non-discrimination (Article 3(b), CRPD).

<sup>8</sup> Committee on Economic, Social and Cultural Rights, General Comment No. 4: The right to adequate housing (Article 11(1) of the Covenant), 1 January 1992; Committee on Economic, Social and Cultural Rights, General Comment No. 13 (Twenty-first session, 1999), The right to education (Article 13 of the Covenant), E/C.12/1999/10, 8 December 1999; Committee on Economic, Social and Cultural Rights, General Comment No. 14 (2000), The right to the highest attainable standard of health (Article 12 of the Covenant), E/C.12/2000/4, 11 August 2000; Committee on Economic, Social and Cultural Rights, General Comment No. 19, The right to social security (Article 9 of the Covenant), E/C.12/GC/19, 4 February 2008.

The rights to equality and choice under Article 19 of the CRPD are civil and political rights and are therefore "immediately applicable". The obligation of the State to provide a range of services brings aspects of the right to live in the community within the realm of social and economic rights. This means that lawyers can argue that funding provided to segregating institutions should be diverted into community support services. Again, this need not happen immediately, but the government does need to have a plan in place with a reasonable timeline containing specific and measurable milestones.

Economic and social rights carry both "positive" and "negative" obligations for States. A negative obligation means that the government must refrain from interfering in the exercise of a right. A positive obligation means that a government must actively take steps to protect, respect and fulfil rights. Take, as an example, a government which refuses to reform its guardianship laws, and which make it impossible for a particular client to sign contracts for community support services. In this case a court may find that the government has violated the person's economic and social rights because of the failure of the government positive obligation to ensure access to community-based services.

Economic and social rights can be raised in courtrooms. In particular, governments must take clear, measurable steps to realise these rights, and the role for lawyers is to point out when they have chosen not to. Litigating the right to live in the community is particularly challenging when the shift from institutional care to community support services has significant budgetary implications. In these cases, lawyers are frequently required to use budgetary and other statistical data to advance their client's position, and are well-advised to call on the assistance of economists. Whilst complex in nature, such cases can highlight systemic human rights violations linked to bad laws, policies, funding allocations and practices.

There is increasing international recognition of the justiciability of economic, social and cultural rights, and numerous court decisions in this respect. These types of rights are included in many constitutions and laws. Further, the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights (OP-ICESCR) has recently entered into force, creating an individual complaints mechanism to the Committee on Economic, Social and Cultural Rights (CESCR Committee). Despite these developments, many courts remain reticent to

grant relief in the event that economic or social rights are violated, particularly where a solution requires the government to spend money. National courts may say that an individual does not have an enforceable right to any particular service. They may say that the court has no jurisdiction to rule on the allocation of resources because that is a matter for government. These are risks that local lawyers will have to explore using some of the principles set out here and further research.

The UN treaty body which is expert in economic and social rights has said that, "neglect by the courts of their responsibility in this area [of economic and social rights] would drastically curtail the capacity of the courts to protect the rights of the most vulnerable and disadvantaged groups in society." <sup>10</sup> Lawyers can use this argument in the courtroom if the government or the judge tries to justify a government's inaction by saying that the right to live in the community is a social and economic right and therefore the issue lies outside the remit of the court.

It is established international law that minimum core obligations to ensure a basic level of enjoyment of each economic and social right must be met irrespective of the level of the country's wealth.<sup>11</sup> According to the same UN Committee, governments "must demonstrate that every effort has been made to use all resources that are at its disposition in an effort to satisfy, as a matter of priority, those minimum obligations."<sup>12</sup> If governments raise a lack of available resources, lawyers can use the Committee's guidance and cross examine government agents about how exactly they are using the country's resources.

Governments must make maximum use of available resources and work towards continually providing better and more complete fulfilment of all human rights. "Available resources" refers not just to resources existing within the State budget but also to those available from the international community, including the European Union, through international cooperation and assistance.<sup>13</sup>

<sup>9</sup> For further information on litigating economic, social and cultural rights see: International Network for Economic, Social and Cultural Rights (ESCR-Net), <a href="https://www.escr-net.org">www.escr-net.org</a> (last accessed: 24.09.2014).

<sup>10</sup> Committee on Economic, Social and Cultural Rights, General Comment No. 3: The nature of States Parties' Obligations (Article 2, Para. 1, of the Covenant), 14 December 1990, at para. 10.

<sup>11</sup> Ibid.

<sup>12</sup> Ibid at para. 10.

<sup>13</sup> Ibid at para. 13. See also Article 32 of the CRPD, on international cooperation.

European Court of Human Rights, "Persons with disabilities and the ECHR", (Strasbourg: July 2014), available at <a href="http://www.echr.coe.int/Documents/FS\_Disabled\_ENG.pdf">http://www.echr.coe.int/Documents/FS\_Disabled\_ENG.pdf</a> (last accessed: 24 September 2014); European Court of Human Rights, "Detention and mental health" (Strasbourg: January 2014), available at <a href="http://www.echr.coe.int/Documents/FS\_Detention\_mental\_health\_ENG.pdf">http://www.echr.coe.int/Documents/FS\_Detention\_mental\_health\_ENG.pdf</a> (last accessed: 24 September 2014); European Court of Human Rights, "Mental health", (Strasbourg: May 2013), available at <a href="http://www.echr.coe.int/Documents/FS\_Mental\_health\_ENG.pdf">http://www.echr.coe.int/Documents/FS\_Mental\_health\_ENG.pdf</a> (last accessed: 24 September 2014); and Peter Bartlett et al, Mental disability and the European Convention on Human Rights, (Leiden: Martinus Nijhoff, 2007).

#### 4(B)(ii). Liberty

In MDAC's experience, people in institutions frequently want to gain their freedom. One of the ways a lawyer can help is by arguing that the client is (a) detained, and (b) their detention is unlawful. The European Court of Human Rights (ECtHR) has established case law on liberty and detention of people with mental disabilities. <sup>14</sup> The proposition that laws can allow States to lock up people with mental disabilities – for whatever purpose – is contentious legal territory since Article 14 of the CRPD provided that in no case should disability justify detention. Numerous controversies have surfaced in this connection which are beyond the scope of this handbook to assess in detail. It is, however, advisable for lawyers entering this field to consider arguments likely to be used by governments to justify a deprivation of liberty, and be ready to challenge those based on a disability or diagnosis.

In Stanev, the ECtHR established for the first time that the involuntary placement of a person with a disability in an institution constituted a deprivation of liberty under Article 5 of the European Convention on Human Rights (ECHR) which sets out the right to liberty. The Court held that Mr Stanev should have had access to a court proceeding to challenge his deprivation of liberty, and should have had access to a legal system which could award compensation for unlawful detention. The ECtHR further held that the need for housing and social services could not be used to justify a deprivation of liberty and that people with mental disabilities should have a say in what services they receive and where they receive them:

[T]he objective need for accommodation and social assistance must not automatically lead to the imposition of measures involving deprivation of liberty. The Court considers that any protective measure should reflect as far as possible the wishes of persons capable of expressing their will. Failure to seek their opinion could give rise to situations of abuse and hamper the exercise of the rights of vulnerable persons. Therefore, any measure taken without prior consultation of the interested person will as a rule require careful scrutiny. 15

In Mr Stanev's case, one of the main points was that, as a person under guardianship, he was stripped of his decision-making rights and so was prohibited from deciding to leave the institution. The Court here addressed the issue of legal capacity, which is dealt with under Article 12 of the CRPD. <sup>16</sup>

Lastly, lawyers should remember that the opposite of detention is freedom; the opposite of a locked door is an open one. The lawyer should act on the client's instructions, with the knowledge that the remedy in a claim which relies solely on the right to liberty of a person in an institution may simply amount to letting the client leave the institution: this may be what the client wants, but the client may find him or herself living on the streets. MDAC recommends a more holistic approach to persuade the court to order the government to provide community support services, as discussed in section 4(B)(i), above.

#### 4(B)(iii). Privacy, family and home

A person in an institution is restricted from doing things that many of us take for granted, such as going to the shops, making a cup of coffee, finding a job or taking a walk in the park. In rights terms too, institutionalisation is linked to other rights violations, such as the right to privacy, the right to physical and mental integrity, the right to liberty and freedom of movement, the right to freedom from exploitation, violence and abuse, and sexual and reproductive rights. Many of these rights are set out in both the CRPD and the ECHR. These, or similar rights such as the right to dignity, may be set out in the country's constitution.

Being forced to live in an institution can constitute a significant interference with a person's private and family life. Institutional life is usually driven by strict house rules and a rigid daily routine, which might include taking medication on a daily basis against their will and/or other coercive and intrusive medical treatments. The closed nature of the institution and the restrictions on leaving can deter the client from forming any relationships with others outside the institution. Staff of institutions sometimes censor post. <sup>17</sup>

Any legal provision which supports the right to autonomy can be used to challenge such restrictions. Article 22 of the CRPD sets out a duty on governments to enable persons with disabilities "to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life" and, to achieve that, governments must boost their "habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services".

Article 8 of the ECHR establishes the right to respect for private and family life, home and correspondence. There is much case law on these issues, but not in the context of disability institutionalisation, where the ECtHR has preferred to find violations of other rights such as the right not to be subjected to degrading treatment or the right to liberty. In Staney, despite finding a string of violations, the ECtHR did not find a violation of Article 8, however two dissenting judgments regretted that the Court chose not to investigate the Article 8 claims. The Bulgarian judge identified legal capacity as "the primary issue" in the case. She noted that the government offered no justification for ignoring Mr Stanev's preferences and that "instead of due assistance from his officially appointed guardian, the pursuit of his best interests was made completely dependent on the good will or neglect shown by the guardian". 18 Again, the link between institutionalisation and legal capacity was made.

The lack of Article 8 jurisprudence is a gap in the Court's jurisprudence related to the institutionalisation of people with disabilities, <sup>19</sup> and represents a clear target for strategic litigation.

<sup>15</sup> Stanev v. Bulgaria, supra note 4, para. 153.

<sup>16</sup> See Chapter 5(A) for strategies on how to overcome legal capacity barriers.

<sup>17</sup> Censoring post may constitute a barrier to accessing justice: see 4(B)(v)., below

<sup>8</sup> Stanev v. Bulgaria, supra note 4, Partly Dissenting Opinion of Judge Kalaydjieva.

<sup>9</sup> The Court also decided not to consider Article 8 claims in Kędzior v. Poland, supra note 5, and Mihailovs v. Latvia, Judgment of January 2013, Application No. 35939/10.

#### 4(B)(iv). Non-discrimination

People with mental disabilities have historically been placed in institutions because of their perceived incompetence to take care of themselves. Equality underpins Article 19 of the CRPD, which establishes an "equal right" of persons with disabilities to live in the community "with choices equal to others".

The CRPD prohibits discrimination which it defines as "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation". Reasonable accommodation means "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".<sup>20</sup>

Governments must implement the right to non-discrimination immediately. This means that governments cannot progressively realise the right: they must immediately put laws and policies in place to prohibit and prevent any discriminatory act.<sup>21</sup>

A leading case which establishes that segregation of people with disabilities constitutes discrimination is the 1999 United States Supreme Court case of Olmstead v. L.C.<sup>22</sup> This case held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.<sup>23</sup> In that case, the U.S. Supreme Court found that segregation in institutions constituted discrimination against people with mental disabilities because they were forced to give up their liberty in order to obtain services.

The placement of people with mental disabilities in institutions rather than providing services for them in the community is often a failure to provide reasonable accommodation. As noted above, Article 5(3) of the CRPD sets out an obligation on governments to take steps to provide such adjustments in order to promote equality and eliminate discrimination.<sup>24</sup>

Similarly, Article 14 of the ECHR sets out a right to non-discrimination in the application of all other ECHR rights. A lawyer could argue that placement in an institution is a violation of the right to liberty, and that because it is only people with mental disabilities who are subjected to this arbitrary form of detention, there is a violation of the right to non-discrimination under Article 14 of the ECHR. Unlike Article 14 of the ECHR itself, the more recent prohibition on discrimination contained in Protocol 12 to the ECHR is not limited to the enjoyment of other rights.

Discrimination arguments are more difficult to put together than they first seem. The State will likely argue that institutions do not constitute discrimination in a similar way that hospitals do not discriminate against ill people or schools discriminate against young people: they will argue that institutions provide services for people in need, a welcome service because the alternative is no services. In response, lawyers representing people with disabilities in such cases will need to argue that the failure to provide services in the community constitutes discrimination in the enjoyment of the right to community living.

One of the central arguments likely to be posed by governments is that institutional care is beneficial to the person with a mental disability. Challenging such claims require some effort, including producing testimony and medical evidence showing the negative impact on their physical or psychological health, as well as research and statements from international bodies on the benefits of community living. The latter can be found from numerous sources, including the Council of Europe Committee of Ministers Resolutions, UN General Assembly Resolutions, and reports of Special Rapporteurs. Lawyers may also wish to cite promising practices from pilot projects on the right to community living.

#### 4(B)(v). Access to justice

Even before making a claim, the client has to find someone who can help. "Access to justice" means a person's right to a just and timely remedy for violations of their rights. It applies to all aspects of the justice system, whether that is a criminal case, a family case or an administrative case. It includes all judicial proceedings such as investigations, tribunals as well as non-judicial mechanisms such as mediation and alternative dispute resolution procedures. The justice system is the route through which all other rights violations are addressed. If a person cannot access justice, they cannot seek redress for the injustices they have suffered, and injustices will continue for other people too.

<sup>20</sup> Article 2, CRPD.

<sup>21</sup> For more on progressive realisation, see the discussion in 4(B)(i)., above.

<sup>22</sup> Olmstead v. L.C., 527 U.S. 581 (1999).

<sup>23</sup> United States Department of Justice (Civil Rights Division), "Olmstead: Community Integration for Everyone", (undated), available at <a href="http://www.ada.gov/olmstead/olmstead\_about.htm">http://www.ada.gov/olmstead/olmstead\_about.htm</a> (last accessed: 24 September 2014).

<sup>24</sup> The CRPD Committee has stated repeatedly in its Concluding Observations that States Parties to the Convention must include denial of reasonable accommodations within their anti-discrimination laws. See, for example, Committee on the Rights of Persons with Disabilities, Concluding Observations on the Initial Periodic Report of Hungary, 2013, CRPD/C/HUN/CO/1, 22 October 2012, paras. 21-22, available at <a href="http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symbolno=CRPD%2fC%2fHUN%2fCO%2f1&lang=en">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx2symboln

Article 13 of the CRPD establishes an obligation on governments to "ensure effective access to justice for persons with disabilities on an equal basis with others". This requires adjustments in any justice process "in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages". People with mental disabilities, like everyone else, interact with the justice system in various ways. They may be victims, witnesses, defendants, alleged offenders, convicted offenders, or have a stake in civil and administrative proceedings. This includes guardianship proceedings and legal proceedings brought to challenge a client's institutionalisation.

Everyone faces challenges in accessing justice systems; legal language or jargon is often confusing and dense and legal procedures are frequently long and complex. Yet many legal systems continue to expect people with disabilities to participate without adjusting the procedures to accommodate their needs.<sup>25</sup>

Access to justice may be especially difficult for a person in an institution because they are likely to face a variety of information barriers. These barriers might include simply not knowing who can help them or how to contact someone to help them. Practical barriers can include lack of access to a telephone or the internet, or financial barriers where legal aid is not made available.

If a person is under guardianship, accessing justice systems may be virtually impossible without the agreement of the guardian. Guardianship systems frequently remove the right for people with disabilities to sign a power of attorney and/or instruct a lawyer, meaning that only guardians can initiate proceedings on their behalf. Where the guardian does not agree, the barrier to accessing justice can seem insurmountable.

How can lawyers deal with these barriers? Article 13 of the ECHR sets out that everyone should have access to domestic remedies where they have arguably suffered a substantive human rights violation. The remedy available must be "effective" in law and practice. <sup>26</sup> The case of *Stanev* established that, even where there was a procedure available to Mr Stanev to restore his legal capacity, the remedy was not effective where it did not provide for compensation. <sup>27</sup>

At the national level, lawyers should look for constitutional guarantees of access to justice or the direct applicability of the international provisions outlined above. The ECtHR and UN treaty bodies were established to ensure that there are (internationally, at least) remedies for violations of human rights. Exhaustion of domestic remedies is often a barrier to accessing these international remedies but is less so in cases of violations of Article 13 of the ECHR where there is no effective remedy nationally. "Effective" includes a time guarantee: the remedy should not take too long. In any event, the remedy must have sufficient enforcement powers, and though it need not be judicial, sometimes the seriousness of the violation requires a judicial remedy.

#### CRPD Committee individual complaint

Accessing justice at the national level may prove fruitless, as there may be few proceedings available. In cases where there is no effective and available domestic remedy, bringing an individual complaint directly to the CRPD Committee under the Optional Protocol to the CRPD is another possible alternative for securing justice.<sup>31</sup>

Articles 6, 7 and 8 of the Optional Protocol also set out an inquiry procedure. The CRPD Committee can initiate an inquiry if there are "grave or systematic violations" of the CRPD in a particular country. Lawyers can help to initiate inquiries where the institutionalisation of their client reflects a wider discriminatory system. Such requests require arguments backed by statistics and data, making a forensic link between widespread violations of Articles 5, 12, 13 and 19 and the acts of government and local municipalities.

#### European Social Charter

Another route to accessing justice is the underused procedure under the European Social Charter. The right to live in the community engages the right of people with disabilities to social integration under Article 15 of the Council of Europe's 1996 Revised European Social Charter. The thrust of Article 15 is the promotion of independence and participation in the community for people with disabilities. Article 15(3) includes the obligation to provide access to transport and housing in order to promote full social integration. In addition, the Revised Charter includes a cross-cutting prohibition on discrimination in Article E.

<sup>25</sup> See the section on discrimination and reasonable accommodation, 4(B)(iv). above.

<sup>26</sup> McGlinchey and Others v. the United Kingdom, Judgment 29 April 2003, Application No. 50390/99, ECHR 2003V, at para. 62.

See also, among others: Anguelova v. Bulgaria, Judgment 13 June 2002, Application No. 38361/97; and Assenov and Others v. Bulgaria, Judgment 28 October 1998, Application No. 24760/94.

<sup>28</sup> Kudła v. Poland [GC], Judgment 26 October 2000, Application No. 30210/96, ECHR 2000XI.

<sup>29</sup> Keenan v. the United Kingdom, Judgment 3 April 2001, Application No. 27229/95.

<sup>30</sup> Ramirez Sanchez v. France [GC], Judgment 4 July 2006, Application No. 59450/00.

<sup>31</sup> This avenue is available for people where the alleged violation of the CRPD happened in a country which has ratified the Optional Protocol to the CRPD. More solutions are presented in Chapter 5.

<sup>32</sup> The State concerned must not have opted out of the inquiry procedure on ratifying the Optional Protocol to the CRPD.

There are several limitations on the use of this mechanism related to whether the country has submitted itself to the collective complaints mechanism, which version of the ESC it has ratified, and which Articles it has accepted. Nonetheless, litigation under the ESC can still secure some of the rights required for full inclusion. This can overcome numerous barriers related to litigating on behalf of individual clients such as the procedural barriers for people deprived of legal capacity and issues of pressure and coercion by guardians and staff of institutions. Further, there is no requirement to exhaust domestic remedies and no time limit for lodging complaints.

#### 4(B)(vi). Fair trial

In the Stanev case, the ECtHR held that the placement of a person with a disability in an institution against their will, on the authority of a guardian, and without access to an effective remedy, constituted a violation of Article 6(1) of the ECHR. This relates to a "right to a court" for those who have suffered an arguable human rights violation.<sup>33</sup> Access to a court must be "practical and effective" and limitations placed on it must not restrict the access of the person to the courts in such a way or to such an extent that the very essence of the right is impaired. Such limitations must pursue a legitimate aim and have a reasonable relationship of proportionality between that aim and the means employed to achieve it.<sup>34</sup>

Reasonable accommodation is also an important feature of a fair trial. If a person needs an interpreter and does not receive one their meaningful participation is compromised and this may lead to an unfair trail.

In finding a violation of Article 6(1) of the ECHR in the Stanev case, the Court noted that access to a court is one of the most fundamental procedural rights for the protection of people deprived of their legal capacity.<sup>35</sup> This is particularly crucial when acting for people under guardianship, and where domestic procedures of review are inadequate.

#### 4(B)(vii). Institutional conditions

The living conditions in which people are forced to live in many institutions are appalling and lawyers may instinctively want to challenge these first. The reason that this topic appears last in the arguments pool is that lawyers should exercise caution about the remedies they request in such cases. Governments and donors frequently choose to renovate institutions when the investment should have gone into establishing community support services. New radiators in an institution may make the place warmer, but renovations solidify institutions as the default option, to the detriment of ensuring inclusion. In legal terms, poor conditions may constitute torture or inhuman and degrading treatment or punishment, in violation of Article 3 of the ECHR and Article 15 of the CRPD.

Both these provisions require governments to actively take steps to prevent torture or ill-treatment. Article 15 specifies that they must take "all effective legislative, administrative, judicial or other measures" to prevent persons with disabilities from being subjected to such treatment, on an equal basis with others. If Article 15 is being considered, lawyers should also consider arguing other CRPD points, including:

- a) Article 16: freedom from exploitation, violence and abuse;
- b) Article 17: respect for physical and mental integrity;
- c) Article 25: right to health, including consent to treatment.



Torture, as the most serious violation of the human right to personal integrity and dignity, presupposes a situation of powerlessness, whereby the victim is under the total control of another person. Persons with disabilities often find themselves in such situations, for instance when they are deprived of their liberty in prisons or other places, or when they are under the control of their caregivers or legal guardians. In a given context, the particular disability of an individual may render him or her more likely to be in a dependent situation and make him or her an easier target of abuse. However, it is often circumstances external to the individual that render them "powerless", such as when one's exercise of decision-making and legal capacity is taken away by discriminatory laws or practices and given

<sup>33</sup> See, inter alia, Roche v. the United Kingdom [GC], Judgment 19 October 2005, Application No. 32555/96, ECHR 2005-X at para.117, and Salontaji-Drobnjak v. Serbia, Judgment 13 October 2009, Application No. 36500/05, at para. 132.

<sup>34</sup> See, among many other authorities, Cordova v. Italy, Judgment 30 January 2003, Application No. 40877/98, ECHR 2003-I at para. 54, and Fayed v. the United Kingdom, Judgment 21 September 1990, Application No. 17101/90, Series A no. 294-B, at para. 65.

<sup>35</sup> Stanev v. Bulgaria, supra note 4, at para. 241.

For example, the European Commission has spent an estimated 30 million EUR on renovating institutions in Romania which warehouse an estimated 18,000 people with disabilities. See: Mental Disability Advocacy Center, "European Commission Funding of Disability Segregation and Abuse Breaches International Law", (Budapest: MDAC), available at <a href="https://www.mdac.org/Romania">www.mdac.org/Romania</a> (last accessed: 24 September 2014).

<sup>37</sup> UN General Assembly, Torture and other cruel, inhuman or degrading treatment or punishment: note by the Secretary-General, 28 July 2008, A/63/175, para. 50.

## UN Convention against Torture, Article 1

"[T] orture" means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions.

The UN Special Rapporteur on Torture has stated that the requirement of intent in the above definition "can be effectively implied where a person has been discriminated against on the basis of disability." This should be read alongside Article 2 of the CRPD which clarifies that denial of reasonable accommodation is a form of discrimination. 39

The failure to provide reasonable accommodations to a person with a disability in a place of detention, such as a mental health or social care institution, may amount to torture or inhuman or degrading treatment.<sup>40</sup> Article 3 of the ECHR requires States to protect the physical wellbeing of people deprived of their liberty. This includes ensuring that:

- a person is detained in conditions which are compatible with respect for his or her human dignity,
- the manner in which the person is detained does not subject them to distress or hardship of an intensity exceeding the unavoidable level of suffering inherent in detention, and
- given the practical demands of imprisonment, the person's health and wellbeing are adequately secured by, among other things, providing the person with healthcare services.<sup>41</sup>

Stanev was the first case in which the ECtHR found that conditions in a social care institution constituted a violation of Article 3 of the ECHR. The ECtHR has found violations of both the substantive (the duty to prevent harm) and procedural obligations (the duty to investigate) of the State under Article 3 in the context of the physical restraint of a person with a mental disability in *Bureš v Czech Republic*. The ECtHR has also found violations of Article 3 in the context of denial of adequate medical treatment, <sup>42</sup> rape, <sup>43</sup> force-feeding and overmedication, <sup>44</sup> intentional humiliation, <sup>45</sup> and segregation. <sup>46</sup>

In assessing the severity of pain and suffering, a court must take into consideration all of the circumstances of the case and conduct an evaluation from both the subjective perspective of the victim, and from the objective perspective of an external viewer.<sup>47</sup> Lawyers acting for a person with a mental disability should ensure that the judge has a full report setting out how the person's disability has impact on their experience of illtreatment. For example, a person's disability may inhibit their ability to defend themselves and make them appear as easy targets for abuse. It may intensify their experience of particular acts (increased fear or physical effects) while acts of torture or ill-treatment may exacerbate or cause a deterioration in a psycho-social condition or result in the acquisition of new mental health issues such as post-traumatic stress disorder. Consideration must also be given to other aspects of the individual's identity such as their gender, HIV or other health status, age or religion.

Jurisprudence of the UN Committee against Torture holds that the State must protect marginalised individuals against the risk of torture or ill-treatment. The UN Special Rapporteur on Torture has also recognised this "heightened obligation" with regard to marginalised people who are at a heightened risk of abuse. The clarifies that, "the State's obligation to prevent torture applies not only to public officials, such as law enforcement agents, but also to doctors, health-care professionals and social workers, including those working in private hospitals, other institutions and detention centres". These are all statements which lawyers can use in the courtroom.

<sup>38</sup> Ibid, para. 49.

<sup>39</sup> Set out in section 4(B)(iv). above.

<sup>40</sup> Z.H. v. Hungary, supra note 6.

<sup>41</sup> Kudła v. Poland, supra note 28.

<sup>42</sup> Ilhan v. Turkey, Judgment 27 June 2000, Application No. 22277/93. See also Selmouni v. France [GC], Judgment 28 July 1999, Application No. 25803/94, ECHR 1999-V pages 96-105

<sup>43</sup> Aydin v. Turkey [GC], Judgment 25 September 1997, Application No. 23178/94.

<sup>44</sup> Nevmerzhitsky v. Ukraine, Judgment 5 April 2005, Application No. 54825/00.

<sup>45</sup> Selmouni v. France, supra note 42.

<sup>46</sup> Keenan v. the United Kingdom, supra note 29.

<sup>47</sup> Ireland v. the United Kingdom, Judgment 18 January 1978, Application No. 5310/71, Series A no. 25.

<sup>48</sup> Committee against Torture, General Comment 2: Implementation of Article 2 by States Parties, CAAT/C/GC/2, 24 January 2008, at para. 21.

<sup>49</sup> Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, A/HRC/22/53, 1 February 2013, para. 26.

<sup>50</sup> Ibid, para. 24.

The UN Special Rapporteur on Torture has highlighted that serious violations and discrimination are often masked as "good intentions" in the context of medical treatment.<sup>51</sup> People in institutions are often subjected to practices such as physical and chemical restraint, seclusion, electro-convulsive therapy (ECT), sterilisation, forced abortion or denial of abortion, or overmedication for the stated purposes of care, therapy, control or because it is in their "best interests". Inevitably in a courtroom, a healthcare or social care institution will claim that what happened to the client was beneficial: the institution provided safety, care and therapy. As the Special Rapporteur has pointed out, the issue of consent is crucial:

Whereas a fully justified medical treatment may lead to severe pain or suffering, medical treatments of an intrusive and irreversible nature, when they lack a therapeutic purpose, or aim at correcting or alleviating a disability, they may constitute torture and ill-treatment if enforced or administered without the free and informed consent of the person concerned.<sup>52</sup>

If a lawyer finds a client who has suffered grievous abuse or neglect, it may be argued that the institutionalisation and what happened to the client constitute torture.<sup>53</sup>

Article 4(1)(d) of the CRPD requires States to refrain from engaging in any act or practice inconsistent with the CRPD and "to ensure that public authorities and institutions act in conformity with [it]." Article 4(1)(e) requires States to take all appropriate measures to eliminate discrimination "by any person, organization or private enterprise". Lawyers should raise this provision to argue against rules of liability which may be used by the State to argue that they have no liability in institutions that are privately owned or that they cannot be liable for the actions of individual staff members. This CRPD provision establishes procedural obligations but also opens the possibility for arguing substantive liability of the State even where the direct link is difficult to make.



<sup>51</sup> Ibid, para. 49.

<sup>52</sup> Ibid, para. 47.

<sup>53</sup> Ibid, para. 70: "Inappropriate or unnecessary non-consensual institutionalization of individuals may amount to torture or ill-treatment as use of force beyond that which is strictly necessary."

#### 4(C). Scenarios

To illustrate the arguments pool, five hypothetical scenarios are set out below to which the arguments can be applied. The section gives lawyers a sense of the types of cases that they may find themselves litigating to secure the right to live in the community. The first three scenarios concern people who

are detained in institutions and consider how the facts can be framed as violations of international human rights law. The following two scenarios consider issues arising for people living in the community who are denied access to specialised services and/or to services available to the general public.

#### 4(C)(i). Anna lives in an institution and wants to get out

#### Facts

Anna has a job and lives in her own home. She has mental health issues. Her relatives get a medical report and a court restricts her legal capacity. The guardianship office of the local government is appointed as her guardian. She does not want to be under guardianship, and has asked the courts several times to reverse their decisions. The courts have rejected her requests.

The guardian signs a contract with a social care institution to provide residential services for Anna. No one informs her about this decision or the reasons for it. Anna is not allowed to take any decisions in the social care institution, and is forced to take sedatives at night, despite her objections. She is not allowed to telephone anyone without the staff listening, and staff read letters which she sends and receives. Anna wants to go home and have her old life back.

#### Discussion

This is a typical scenario in many countries of the world. There are many points which a lawyer can argue to help Anna, relying on the arguments pool above:

- 1. Community supports: Anna's right to live in the community has been violated by placing her in an institution.
- 2. Liberty: On the facts, it looks like she is unlawfully detained.
- 3. Privacy, family and home: In the institution her decisions are restricted and the regime constricts her autonomy. Her communications are restricted and censored, she can no longer access the home she owns and she cannot form relationships outside the institution.
- 4. Non-discrimination: Anna has been placed under guardianship and in an institution on the basis solely of her perceived mental disabilities. No other group in society is treated like this.
- 5. Access to justice: She has no avenue to challenge her institutionalisation or appeal the decision of the guardian.
- 6. Fair trial: Anna was not informed about her guardianship or given any opportunity to challenge her detention, so her fair trial rights are engaged.
- 7. Conditions: The cumulative effect of being forcibly treated with medication and being detained in an institution may amount to ill-treatment under Article 3 of the ECHR or Article 15 of the CRPD.

#### 4(C)(ii). Boris faces retribution

#### Facts

Ten years ago Boris was placed under guardianship on the basis of a diagnosis of mental illness. Since then he has lived at home with his mother. His mother develops Alzheimer's disease and is in turn placed under guardianship. Boris's sister becomes guardian of both him and their mother. Without consulting him, she places Boris in a social care institution where Boris is allowed relative freedom to choose what he does each day, to come and go as he pleases. Nevertheless, he does not want to live in an institution and wants to go home. As there is no possibility of doing this while under guardianship, he initiates a review of his guardianship and represents himself during the court proceeding.

The court rejects his claim on the basis of a psychiatrist's opinion which states that his mental illness is permanent, and also refuses Boris's request to obtain a second opinion. An appeal court upholds the placement under guardianship. Boris approaches a lawyer but as a person under guardianship he

cannot legally sign a power of attorney: only his guardian can sign it on his behalf. The lawyer says he will help anyway, which Boris is pleased about. Reacting to his efforts to challenge the guardianship and institutionalisation, his sister tells Boris she will transfer him to an institution further away unless he stops contact with the lawyer. Boris does not want to be transferred and agrees to sign a paper saying he will not contact the lawyer.

#### Discussion

These facts may seem far-fetched but are based on a case in which MDAC has been involved. Lies, intimidation, and threats are common when placing people into institutions and blocking them from getting out. In this example we will consider issues of access to justice and the right to a fair trial.

 Community supports: Boris is in an institution where he doesn't want to be, so his right to live in the community is being violated.

- 2. Liberty: If Boris cannot get out of the institution when he wants, he is detained and his right to liberty is restricted.
- 3. Privacy, family and home: Depending on the setup of the institution, Boris's right to a private life may also be restricted.
- 4. Non-discrimination: Similar to Ann, Boris has been placed in an institution only because of his label as having a mental disability. Lawyers could argue a discrimination point on these grounds.
- 5. Access to justice: Boris's guardian has tried to block Boris from seeing his lawyer, and therefore his access to justice is being denied. In this case, the authorities are being inconsistent: they are dismissing Boris's legal capacity to decide to leave the institution, but implicitly recognising his legal capacity by accepting the validity of his signature, which was obtained through coercion.
- 6. Fair trial: This right may be engaged as the court has relied on one single expert opinion which states that Boris's condition is permanent: in most national laws which have guardianship, this is not a sufficient justification for removing a person's legal capacity. The fact that a court has rejected a second opinion may also raise fair trial issues.
- 7. Conditions: The UN Special Rapporteur on Torture has raised the possibility that wrongful detention in an institution may amount to ill-treatment in and of itself. Here Boris is detained in an institution for people with Alzheimer's disease, so lawyers may raise a claim highlighting the likely detrimental effects of long-term institutionalisation.

#### 4(C)(iii). Charles lives in an institution with appalling conditions

#### **Facts**

Charles was placed in a social care home at the age of three and remained in the institution throughout his childhood. When he turned 18 he was placed under guardianship and transferred to an adult institution where the director became his guardian. The institution is located in an isolated part of the country and with extremely limited accessibility from the outside. The living conditions in the institution are horrific: there is no proper heating during the winter, residents have to sleep on bare bedframes, they do not have their own individual clothes and the stinking toilets do not give any privacy. Charles has tried to escape several times but each time the police brought him back to the institution.

#### Discussion

- 1. Community supports: Charles is denied his right to live in the community, so lawyers should argue this point to get him services in the community.
- 2. **Liberty:** Charles is detained with no opportunity to leave, and has been brought back when he escaped. He has no legal avenues to challenge his detention in the institution, nor to seek compensation for violation of his rights. Lawyers should argue Articles 5(4) and 5(5) of the ECHR.

- 3. **Privacy, family and home:** Article 8 of the ECHR could be engaged because of the restrictions on Charles's life in the institution.
- 4. Non-discrimination: Like the previous two examples, Charles seems to have been placed in the institution because of a label of mental disability, so lawyers should look into arguing a discrimination point.
- 5. Access to justice: Lawyers may raise this if they have difficulties in bringing an action to court. Charles only accessed a lawyer when an NGO visited the institution and spoke to him because he couldn't reach one otherwise.
- 6. Fair trial: Charles's placement under guardianship when he reached eighteen may raise a fair trial issue which the lawyer could raise.
- 7. Conditions: This is clearly an issue. It is vital that the remedies attached to these arguments make it clear that renovating the institution is insufficient because the main problem is Charles's institutionalisation. The remedy to that abuse is evacuation and supports to enable Charles to live in the community.

#### 4(C)(iv). Dora lives in the community but is denied support services

#### Facts

Dora is aged 51 and recently left a psychiatric institution where she lived for ten years. In the community she has experienced serious difficulties in finding and maintaining appropriate housing and other support services. The country she lives in does not have a well-developed system of community-based support services for people with mental disabilities. Having been segregated for a decade, she has no friends or other supports to rely on in the community. She has been homeless for several periods, and ended up back in the psychiatric institution for several months at a time.

#### Discussion

1. Community supports: It is clear that the State has provided Dora with no or inadequate supports to enable her to live in the community. This is a point which lawyers should litigate strongly. Article 19(b) of the CRPD requires governments to roll out a network of community support services for people with mental disabilities. If there are in practice no options other than living in a social care institution, Dora has to choose between institutionalisation and homelessness. Lawyers should argue that this makes a mockery of the notion of "choice" in Article 19(a), and the obligation to provide services under Article 19(b). Lawyers could also

- argue that Dora's rehabilitation rights under Article 26 of the CRPD have been violated. They could also argue that her right to housing under Article 28 of the CRPD has been compromised.
- Liberty: Dora has her liberty now, but lawyers may want
  to investigate the legality of her detention in the psychiatric
  hospitals, especially if the only reason she was living
  there, and was readmitted there, was because of a lack of
  community support services.
- Privacy , family and home: A lawyer could argue that Dora's right to respect for a home is violated if she has nowhere to live.
- 4. Non-discrimination: This may be an issue, depending on the availability of community housing and other supports for people without mental disabilities. Not providing reasonable accommodation in the manner in which housing and other

- supports are provided may mean that the State has taken a discriminatory approach to Dora as a person with mental health issues (which constitutes disability-based discrimination for the purposes of the CRPD and the ECHR).
- 5. Access to justice: Lawyers should ask questions about the availability of information to Dora on how to litigate the violations of her other rights, how to appeal negative decisions in relation to housing, and access to legal aid to assert her rights.
- 6. Fair trial: This will only become an issue if Dora has access to the justice system in the first place and then there is a lack of reasonable accommodations or other issues with the proceedings.
- 7. Conditions: This is not an issue in this case.

#### 4(C)(v). Erik is a child who goes to special schools but who faces adulthood with no services

#### Facts

Erik is fourteen years old and has intellectual disabilities and autism. He lives at home with his mother, attends a special school but receives no other community support services. His family are worried about what will happen when he turns eighteen. The person at the local government responsible for adult care has told Erik's mother there are no services which can help Erik live at home and they recommend sending him to the "Capital social care institution for adults with mental disorders" which is in the suburbs of the capital city (50km away from their home), where he will be cared for. Erik's mother does not want Erik to be placed in an institution. There is no state-funded legal service to help Erik's mother.

#### Discussion

1. Community supports: If Erik is forced into an institution and consequently forced to give up his rights to home, education or work due to a lack of community support services, this violates his right to live in the community. Lawyers have time on their side because the local government has until Erik's eighteenth birthday (four years) to put in place an alternative package of support. They should be considering now whether there are any supports he can already be seeking, e.g. a carer to come into the home to assist his mother in

- the short-term, additional skills training on personal care and independent living, the availability of further education classes and so on. Lawyers should gather information on the gaps and assess whether they can be litigated in advance.
- 2. **Liberty:** This is not immediately relevant until he is placed in the institution, a situation the lawyer should be fighting to prevent.
- 3. **Privacy, family and home:** This also will only be engaged when he is institutionalised. At a long-stretch there may be an argument that Erik's right to form relationships with other children is violated by his segregated schooling.
- 4. Non-discrimination: This could be raised to argue that the failure to provide community supports constitutes a failure to provide reasonable accommodations, which amounts to disability-based discrimination.
- 5. Access to justice: If there is no appeal process for sending him to the institution there could be an issue in this case.
- 6. Fair trial: There is no access to legal aid to bring a claim, so Erik's mother would have to rely on a pro bono lawyer, or pay a lawyer herself. These could be raised by the litigating lawyer as impediments in a strategic case, and the lawyer should consider an application in any court proceedings for a grant of legal aid to ensure access to justice for Erik and his mother.





"Rusi is leading his independent life and he continues to be keen to take part in our legal activities advancing his autonomy. He still becomes very nervous if he thinks that somebody is trying to restrict his liberty."

> Aneta Genova Lawyer, MDAC Legal Monitor

## 5.

## Practicalities of litigating the right to live in the community

The present chapter highlights practical issues that lawyers should consider and address in conducting litigation to secure the right to live in the community for people with mental disabilities. Litigation in this area can be complex, drawn out and frustrating for clients and lawyers alike, requiring long-term commitment and a creative and flexible approach. Ensuring the inclusion of people with disabilities in our communities fundamentally challenges an exclusionary approach based on stereotype and prejudice, and targets State structures which are built around guardianship and institutionalisation. As such, it takes on a number of vested interests, including those of guardians, family members, civil servants, staff in institutions and managers, community service providers and government ministries.

Whilst some of these actors may be willing to support a more human rights-based approach, the risk of strong adverse reactions is high. This can lead to a number of risks which lawyers must be prepared for, including intimidation or harassment of the client, pressure to end legal claims, and challenges to the lawyer's credibility and professionalism. A risk management plan is therefore crucial in such cases in order to ensure that strategic litigation will achieve its aim.

The right to live in the community has a strong human element and lawyers must carefully recognise and manage the real difficulties their clients may be experiencing, including as a result of the litigation itself. Clients can be vulnerable to exploitation, abuse and trauma because of their experiences and their disabilities. Lawyers may well be required to alter their practices significantly in order to create stability and an enabling relationship which can sustain the litigation through to conclusion. The risks and benefits of litigation and the potential adverse effects on their clients must be carefully considered by lawyers, and these should be communicated clearly to clients in order that they can make full and informed choices. Mitigating the potential risks is crucial, but even with the best plan in place issues can occur, and lawyers need to play an active role in reducing their effect to the maximum extent possible.

The conundrums presented in this section are drawn from actual issues which MDAC has encountered in its strategic litigation over the past few years. The section is presented in the form of questions which lawyers may have. Under each question are some ideas which can help the lawyer think through and plan. These are not definitive answers as so much is contingent on local facts, law and the lawyer's skillset. Rather, the intention is to encourage lawyers to ask these questions to themselves and their teams in the process of case planning and conduct. MDAC's own learning as an organisation is developing and it welcomes any communication, information and advice from lawyers reading this who want to share their experiences, engage in a conversation or seek advice.

## 5(A). How can I represent someone who has been deprived of their legal capacity?

Many people with disabilities in institutions are under guardianship. In many European countries, deprivation of legal capacity and placement in institutions go hand in hand, with one facilitating the other. Relatives seek to have their family member deprived of their legal capacity in order to place them in an institution, and in some cases the motivation will be to gain control over their assets. Deprivation of legal capacity has practical implications in litigating the right to live in the community and other rights. People deprived of their legal capacity will have a guardian appointed to make

decisions for them. In many cases, they will be under plenary guardianship where all of their legal standing and rights have been stripped from them. In cases where they are placed under partial guardianship and only some of their rights have been removed, the right to instruct legal counsel and/or the right to be represented in court are removed. This can mean that any power of attorney (the document on which a client instructs a lawyer to provide legal representation) is considered null and void and the lawyer will not be considered to be validly instructed. In these cases, lawyers should tread carefully.

#### 5(A)(i). Develop a constructive relationship with the guardian

Guardians have tremendous power over people whose legal capacity is restricted since they control the person's finances, living situation, access to services, and have the power to contract on behalf of the person concerned, among other powers. As a result, guardians can directly and indirectly influence the person's ability to pursue litigation. While the institution of guardianship is in itself a violation of rights under Article 12 of the CRPD, it should not be automatically assumed that an individual guardian will be unsympathetic to the issues. In some instances, for example, a guardian may have been appointed but have been completely inactive in making decisions on the client's behalf. Indeed, they may never even have met the client despite being legally responsible for her/him as they may be appointed as guardian for a large number of people.

In these circumstances, a non-confrontational approach to the relationship to begin with may be best, along with a clear understanding of the guardian's powers and obligations. A lawyer seeking mutually-acceptable solutions may be effective in achieving immediate progress in the specific case. Engaging constructively with a guardian may result in the guardian taking a decision to discharge the client from an institution, or in procuring services within the community to facilitate independent living. An initial friendly approach does

not prevent subsequent strategic litigation to achieve recognition of the past violations of the client's rights and restitution, compensation, rehabilitation and other remedies which may change laws or practices. However, lawyers must be attentive to limitation periods for the initiation of litigation to ensure that pre-litigation negotiation does not result in the barring of subsequent litigation due to statutory time limits.

In other instances there may be no guardian appointed or confusion over who the actual guardian is. For example, in one case which MDAC litigated, the client moved from one region of the country to another when he was discharged from the institution. A guardian was then appointed in the region where the client was moved without displacing the guardian in the former region. One guardian was supportive of his efforts to regain his legal capacity while the other was resistant. It is important to be familiar with the manner in which national law regulates such situations, as it is not unusual to discover that the law lacks provisions ensuring a clear solution. The lawyer should be prepared to capitalise on a period where the client lacks a guardian or where confusion arises. Such situations can create opportunities to have a valid power of attorney signed, to liaise with the guardianship authority so that a trusted friend or family member is appointed as the guardian, or to take steps which enable the client to leave the institution.

#### 5(A)(ii). Displace the guardian

It may be necessary to seek to have a particular guardian removed or their powers restricted in order to give the client choice and autonomy, and to effectuate their evacuation from an institution. The lawyer should establish the legal duties and responsibilities of guardians under the law, identify where such duties are codified and determine how the performance of guardians is overseen. In many systems, the only apparent limitation to a guardian's power is that they act legally. In many jurisdictions, guardians ostensibly have full discretion in making decisions on behalf of the client. Many laws contain little or no obligation on the guardian to solicit the opinion of the person under guardianship, and fewer still have an obligation that the guardian must follow the person's will and preferences as required by Article 12 of the CRPD.

Almost every system has a guardianship authority which oversees the actions of guardians and may require them to act in the "best interests" of the person concerned. They may also require them to file reports on an annual basis about decisions taken and spending incurred. A lawyer can ask for these files to examine decisions by guardians and determine whether they are in compliance with the duties imposed on guardians. This could involve submitting a legal request to the guardianship authority or requesting an Ombudsman or other independent body to investigate.

In many jurisdictions, the court or local authority appoints a family member as guardian. In others, the director of a residential institution can be the guardian. In both scenarios, conflicts of interest may arise, particularly where the guardian will benefit financially or otherwise from decisions they make for people under their guardianship. Lawyers seeking to remove the influence of an unsympathetic guardian should research what national mechanisms exist to challenge conflicts of interest.

The respondents in actions to remove or replace guardians should be carefully considered. Lawyers could consider a number of legal actions, including:

- Challenging the guardianship authority for failing to effectively supervise the actions of the guardian;
- Challenging the guardian her/himself before the guardianship authority; or
- Challenging a legal or regulation gap through, for example, the constitutional or supreme court.

Where domestic remedies are lacking or inadequate, the lawyer should investigate the most appropriate international forum to which the case can be brought.

#### 5(A)(iii). Find alternative legal avenues

Some jurisdictions allow NGOs or other interested parties to initiate cases directly in higher courts, for example, where a case engages the public interest, or if it involves a violation of the human rights of specific or even unidentified individuals. In Romania, for example, the Code of Civil Procedure allows anyone to initiate litigation if their "legitimate interests" are harmed. This includes the interests of NGOs in safeguarding human rights and ensuring effective remedies. Prohibiting standing to third parties in the case of serious violations of human rights encourages impunity and lack of accountability on the part of perpetrators. This can be a powerful legal argument where the facts of a case are strong.

It may also be possible to challenge a particular statute, regulation, act or omission as unconstitutional without an actual power of attorney from a specific client. Public interest litigation, class actions or constitutional challenges can provide effective methods of challenging the system of institutionalisation in its totality or specific aspects of the system, without the necessity of having to rely on one particular client or fact pattern. In some countries, these processes may be more speedily resolved than filing a standard legal claim on behalf of an individual client.

Whatever the domestic law says, lawyers should always ask the client to sign a power of attorney which sets out instructions to the lawyer, and this should cover the eventuality of submitting an application to the European Court of Human Rights. That Court accepts cases filed on behalf of people under guardianship, 54 irrespective of whether domestic law prohibits people under guardianship from instructing a lawyer. 55 The Court does not apply the criteria that an applicant must be a "direct victim" in "a rigid, mechanical and inflexible way". 56 It has stated in connection to legal standing that:

Although the primary purpose of the Convention system is to provide individual relief, its mission is also to determine issues on public-policy grounds in the common interest, thereby raising the general standards of protection of human rights and extending human rights jurisprudence throughout the community of Convention States.<sup>57</sup>

The Court has recognised the standing of individuals other than the direct victim taking into account the "victims' vulnerability on account of their age, sex or disability, which rendered them unable to lodge a complaint on the matter with the Court, due regard also being paid to the connections between the person lodging the application and the victim". 58 In the 2014 judgment in Câmpeanu v Romania, 59 the Court further expanded its jurisprudence regarding standing, albeit in a limited manner. In that case, the Court allowed an NGO to bring a case regarding violations of the right to life of a young person with disabilities who died in a psychiatric hospital during a period when he had no guardian appointed but was nonetheless stripped of his legal capacity.

As noted above in section 4(B)(vi)., it is possible to initiate a case directly at the European Court under Article 6(1) of the ECHR if there is no avenue to challenge the placement under guardianship at the national level. <sup>60</sup> Lack of access to courts in this regard represents a continuing violation which can therefore be submitted at any time. Further, an ECHR power of attorney may carry more weight with domestic courts even if the client is denied legal capacity under national law.

Finally, lawyers should consider which alternative judicial or quasi-judicial tribunals are available where a case can be initiated but the rules of standing are less stringent, such as an Ombudsman's office, a national human rights commission or equality body. This includes international tribunals such as the UN Treaty Bodies or the European Committee of Social Rights.

#### 5(A)(iv). Challenge stigma, prejudice and stereotypes directly

Courts and judges may very well reflect the same stereotypes and misconceptions that are prevalent in the rest of society, and they may assume that someone under guardianship is incapable of making any decisions. In societies where people with mental disabilities have been kept out of sight and prevented from

exercising their autonomy, courts may still view guardianship and institutionalisation as protective, rather than restrictive, measures. All lawyers must have a good grounding in very basic arguments against stigma and prejudice and should never assume that courts will be familiar with legal concepts relating

- 54 Stanev v. Bulgaria, supra note 4, among others.
- 55 P, C & S v. the United Kingdom, Judgment 16 July 2002, Application No. 56547/00.
- 56 Karner v. Austria, Judgment 24 July 2003, Application No. 40016/98, para. 25.
- 57 Ibid, para. 26.
- 58 Câmpeanu v. Romania [GC], Judgment 17 July 2014, Application No. 47848/08, para. 103. Note however, the restrictive application of the criteria regarding standing in Nencheva and Others v. Bulgaria, Judgment 18 June 2013, Application No. 48609/06. This case involved the deaths of 15 children and young people with disabilities in a social care home.
- 59 Ibid
- 60 See Stanev v. Bulgaria, supra note 4 and Mikhaylenko v. Ukraine, Judgment 30 May 2013, Application No. 49069/11.
- 61 See section 4(B)(i). above, for a discussion.

to mental disability and human rights. Compile research and arguments to inform judges about supported versus substituted decision-making, and framing this as a human rights issue. Encourage judges to speak to the individual directly and assess

their competence for themselves, rather than relying on expert reports. Commission an independent medical assessment corroborating the client's ability to give free and informed consent to litigation and to give clear instructions.

## 5(B). How do I receive instructions and evidence from my client if she/he is denied access to the outside world?

Clients who live in institutions are generally not allowed to leave the institution. They are therefore not able to gather evidence or to attend independent medical or legal appointments or court dates. Frequently, clients in institutions are denied access to telephones or denied visitors (especially if the lawyer does not have a power of attorney, or if the staff consider the power of attorney to be invalid). People in institutions often lack access to paper, pens and stamps to post letters or get to a post-box to ensure that letters are delivered. Incoming and outgoing mail may also be screened or held by staff or re-routed to the client's guardian. There are often no computers with email capabilities. Information and communication challenges can be immense.

#### 5(B)(i). Become familiar with the client's environment and limitations

Lawyers should visit the institution to meet the client. They should assume that, even if the client has permission to leave the institution, this can change at any time at the discretion of the institution staff or the guardian (if there is a guardian). The lawyer should meet with the director of the institution to assess the extent to which it is possible to develop a cooperative relationship which may facilitate access to the client and the client's access to the outside world. In MDAC's experience, something as simple as a sympathetic staff member or a brief conversation with a roommate who has access to a mobile phone can greatly facilitate the litigation process. The client may be able to identify allies with whom she/he has a positive relationship. Lawyers should also consider whether providing the client with a mobile

phone will reduce the risk that staff will intimidate the client. Such a small action can be a powerful deterrent against staff retribution, and can be comforting to the client.

Visiting the client will provide the lawyer with first-hand information about the reality of their daily life. This is essential to be able to understand the client's perspective, frustrations and limitations, and can ensure that lawyers can gain a clear understanding of their instructions. A visit can reveal additional rights violations such as poor sanitary conditions, inadequate food and nutrition, insufficient staffing levels and other issues relating to the right to health and/or the prohibition of ill-treatment and torture.

#### 5(B)(ii). Find sources of support and information

Where the lawyer is denied access to the institution, it may be helpful to contact service provision NGOs or peer support groups that may have an agreement to access the institution. The office of the Ombudsman or other inspectorate bodies may have a right to access institutions. At the same time, lawyers should consider the evidence which can be gathered without

the client's help, for example, circumstantial evidence, human rights reports by international bodies or NGOs, previous court files from legal capacity proceedings, the guardianship file, information on any property interests from the property register and expert medical evidence.

#### 5(C). What should I do if my client is being harmed?

The closed nature of mental health and social care institutions increases the risk of exploitation, violence and abuse occurring. Often these abuses are carried out with impunity, which means that perpetrators are not punished, so abuses continue unabated. The physical isolation of institutions, placement of people under guardianship and the inherent imbalance of power between residents and staff can all be contributing factors.

The risk of abuse may also be exacerbated by the residents' disabilities which mean that they are not in a position to, or able to, complain to anyone. It may be that there is actually no-one to complain to. Further, it is not uncommon for litigation of this sort to result in threats, intimidation or harassment of the client by her/his guardian, staff or management of the institution, her/his family or from other sources. This may take the form of physical abuse or violence, or psychological or financial abuse, such as moving the client to an isolated institution in terrible conditions or selling off their assets.

Lawyers should be sensitive to the fact that different aspects of a client's identity may increase their vulnerability to particular types of abuse and neglect. The impact of particular practices may be more pronounced for some individuals, causing psychological or physical trauma. For example, inadequate nutrition can have a more severe effect on children or older people than adults. Women are more susceptible to gender-based violence. HIV or other health status, and being from an ethnic minority can play a factor in violence and discrimination amounting to ill-treatment. People with combined physical and mental disabilities may be additionally susceptible to a range of abuses, some of which may be difficult to detect (e.g. feeding people whilst they are lying on their back with the potential of inducing choking).

Depending on the client's instructions, the lawyer's main aim is likely to get the client out of the institution and into the community. But when ill-treatment occurs, the most immediate obligation is to ensure that the client is safe. If the client tells the lawyer that they are at risk of being abused or neglected in the institution or the lawyer becomes aware of these violations during a visit, this section offers some practical steps the lawyer can take to protect the client in the short-term and to facilitate the litigation in the longer term.

#### 5(C)(i). Persuade the authorities to take action

In any sort of abuse or neglect case, lawyers should contact the police unless doing so will place the client in danger. At a minimum, the lawyer could send a strongly-worded letter to the person responsible for the client's care (copying other people in authority) demanding that person to cease and desist from continuing the abuse/neglect, take action to prevent the targeting of clients, and threaten the strongest possible legal action if this does not happen.

Depending on the context, the lawyer could also take the issue of abuse straight to the top of the chain of command of the institution. Often directors do not know what is happening in the wards/departments of the institution which they manage. Lawyers can also inform the relevant supervisory Ministry at the local or central governmental level, and could bring the matter

to the attention of the ombudsperson's office or national human rights commission, if these bodies exist. The lawyer could also alert the guardian of the situation.

If the ill-treatment is the result of actions by a particular staff member, the lawyer can ask the management of the institution to make sure that the staff member and the client do not come into contact with each other. The lawyer can ask for the staff member to be suspended pending an investigation. If this does not happen, the lawyer could find out whether the legal system might grant a restraining order to keep the alleged offender away. In the medium term, initiating disciplinary proceedings at the professional regulatory authority would also be worth considering, particularly where medical or nursing staff are involved.

#### 5(C)(ii). Document and collect evidence

Documenting what is happening is crucial. The more paperwork a lawyer can generate to capture what is happening to the client, the better. The lawyer could think about sending in independent monitors such as an ombudsman's office, human rights NGOs, psychologists or peer-support groups. Everyone

should note down what they see and what they are told, to build up a set of documentation.

It is important to document ill-treatment which can create a strong evidence base for litigation. Lawyers can commission an

independent doctor to examine the client and document injuries or the effects of ill-treatment on their client's physical and mental health. Medical reports should include a description of any injuries and a full record of the client's explanation of how these occurred, as well as the opinion of the doctor as to whether the injuries are consistent with the explanations. The lawyer should ask the client to keep a journal of the date and details of every relevant occurrence. The lawyer can take photographs of injuries and of conditions during visits if possible, and speak to other residents and staff for corroborative statements related to specific incidents or to establish a pattern of facts. The

client's family members or friends may also be able to provide statements regarding any deterioration in the client's physical or mental health since the alleged violations took place.

There may be situations in which the lawyer should consider making a statement. There is the risk that a statement made by a lawyer could be cross-examined, meaning that they then become a witness in future proceedings, and potentially meaning that they can no longer continue to act as legal representative. In such situations, the lawyer should be careful to take account of their professional obligations.

#### 5(C)(iii). Monitoring and accountability

It is likely that instances of abuse and neglect will decrease if staff become aware that they are being monitored. Providing the client with a mobile phone, as suggested above, can be helpful. Getting the inspectorate (such as a human rights commission or ombudsperson's office) involved can also help. Lawyers can check whether these bodies visit the client's institution. If they do not, the lawyer can suggest that they do.

Article 33 of the CRPD requires States to establish "a framework, including one or more independent mechanisms,

as appropriate, to promote, protect and monitor implementation of the present Convention". Governments are not always aware of the extent of violations that happen within institutions and so contacting these mechanisms and calling for them to monitor the institution may result in immediate accountability for alleged perpetrators. In addition, the European Committee for the Prevention of Torture does not have an individual complaints procedure but it welcomes confidential information about which institutions it should inspect during its next visit to the country.<sup>62</sup>

#### 5(C)(iv). Send an urgent appeal to the UN

Under the UN Human Rights Council Special Procedures there are a number of Special Rapporteurs, Independent Experts and Working Groups which accept "urgent appeals" regarding violations of human rights. These mandates can act quickly by organising to visit the State, including the institution in question, and sending communications to governments seeking information and comments, and calling for immediate action to end abuses. They also conduct thematic studies, convene expert consultations, raise public awareness and provide advice. The Special Procedures have thematic focuses so it is important to choose the most relevant Procedure or to send the appeal to several relevant Procedures, asking them to act in concert.

Some relevant Procedures include:

- the Special Rapporteur on Disability;
- the Special Rapporteur on the Right to Health;

- the Independent Expert on the enjoyment of all human rights by older persons;
- the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment;
- the Working Group on Arbitrary Detention;
- the Working Group on the issue of discrimination against women in law and in practice; and
- the Special Rapporteur on violence against women, its causes and consequences.

These can be fast and efficient mechanisms to draw attention to the problem and attract accountability without directly implicating the client in the process, thereby reducing the risk that the client will be subjected to reprisals.

<sup>62</sup> The State in question must be a party to the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment.

<sup>63</sup> More information can be found on the websites of the individual mandates at <a href="http://www.ohchr.org/EN/HRBodies/SP/Pages/Themes.aspx">http://www.ohchr.org/EN/HRBodies/SP/Pages/Themes.aspx</a> (last accessed: 24 September 2014).

#### 5(C)(v). Interim measures

If litigation has already been initiated, consider whether the relevant court can order interim measures to protect the client from abuse, up to and including temporary discharge from the institution pending the outcome of proceedings. Interim measures may also involve a

prohibition on transfer of the client, freezing the guardian's powers in relation to disposal of assets or other measures appropriate to the particular situation. The ECtHR has the power to order interim measures under Rule 39 of its Rules of Procedure.

## 5(D). What should I do if I doubt my client can live independently in the community?

Lawyers who are unfamiliar with the disability rights field have shared with MDAC a range of concerns when faced with the reality of specific cases. <sup>64</sup> One frequently-raised concern is that the lawyer cannot imagine how a particular person in an institution could live outside. After all, the institution provides care and treatment, daily activities, food, clothes and shelter. Lawyers may be concerned that removing the client from an environment like this and expecting them to live alone is unrealistic.

Concerns such as these may increase if the lawyer finds that the client shows symptoms such as difficulty communicating, expressing unclear wishes, is experiencing hallucinations, has slurred speech or an unsteady gait, seems disconnected from her/his surroundings, is unfocused, provides contradictory or irrational information, experiences forgetfulness or aggression, has excessive expectations of litigation, etc. The lawyers are correct: it is unrealistic to expect someone to live alone without any support. But individual, atomistic living is not what the right to live in the community means!

#### 5(D)(i). Get appropriate community-based supports for the client

Everyone has the right to live in the community. The right is not contingent on the type of disability or level of support needed. Lawyers tend to forget that the right to live in the community includes not just the right to decide where and with whom to live, but also to be provided with adequate supports to facilitate this choice. While the primary aim in the short-term may be

for the client to leave an institution, any litigation in this area should include seeking access to appropriate community-based supports on the basis of full respect for the client's will and preferences. This may be through seeking specific remedies in court or simply through identifying existing supports and putting the client in touch with service providers.

#### 5(D)(ii). Interrogate your own prejudices and listen to the client

Lawyers should be alert to their own stereotypes and assumptions and should regularly question and challenge them, as much as anyone else. Many residents in institutions are heavily medicated and have spent years in an institution which removes skills and sometimes hope. Lawyers should work with the client at the preparation stage of litigation: even clients without verbal communication can articulate their wishes and desires about the sort of life they want to lead. Many clients can explain the difficulties they face and what help they need. Becoming familiar with the client and his or her will and

preferences is essential for successfully achieving strategic litigation objectives. If it is not feasible to personally do this work because of time or other resource constraints, a lawyer must work with someone who can. This may be a trusted friend or relative of the client, a social worker or counsellor, or an NGO employee or other form of support worker. But care must be taken to ensure that the client's decisions are those which guide action, and not those of supporters.

<sup>64</sup> For further information on representing people with disabilities see Lana Kerzner, "Providing Legal Services to People with Disabilities" (Arch Disability Law Centre, Toronto: April 2008), available at <a href="http://www.lsuc.on.ca/media/eleventh\_colloquium\_kerzner.pdf">http://www.lsuc.on.ca/media/eleventh\_colloquium\_kerzner.pdf</a> (last accessed: 24 September 2014); and Dr Paul Swift et al, "What happens when people with learning disabilities need advice about the law?" (Norah Fry Research Centre and University of Bristol: July 2013), available at <a href="http://www.legalservicesconsumerpanel.org.uk/ourwork/vulnerableconsumers/Legal%20Advice%20Learning%20Disabilities%20Final%20Report.pdf">http://www.legalservicesconsumerpanel.org.uk/ourwork/vulnerableconsumers/Legal%20Advice%20Learning%20Disabilities%20Final%20Report.pdf</a> (last accessed: 24 September 2014).

#### 5(D)(iii). Use standard legal interview techniques

Clients with mental disabilities may provide contradictory, unclear or insufficient information. This is no different to clients without mental disabilities. Interviewing clients with mental disabilities requires the lawyer to have good interviewing skills and to examine the evidence in the same way as for other cases. Statements by the client which the lawyer thinks are incredible or irrational do not necessarily negate their

credibility. Lawyers should deploy good interview techniques: establish trust, cross-reference information, and repeat questions in different ways. Clients who have been in institutions or have been abused may find it extremely difficult to relive and explain their experiences and may confuse facts. These challenges can undermine the strategic and individual success of the case unless the lawyer identifies and addresses them.

#### A human rights-based approach to lawyering with people with mental disabilities

Good	Avoid
<ul> <li>Speak directly to the client</li> <li>Avoid jargon</li> <li>Ask one question at a time, and allow the client time to answer</li> <li>Give the client your full, undivided and uninterrupted attention</li> <li>Use standard legal interview techniques to evaluate all</li> </ul>	<ul> <li>Directing questions/comments to the client's guardian or support person</li> <li>Dismissing the client's concerns because some of her/his statements are unbelievable or nonsensical</li> <li>Relying primarily on the opinions of experts, including medical experts</li> <li>Using Latin and long sentences</li> </ul>
statements and evidence  Listen to the client: they are the experts on their own situation	<ul> <li>Asking multiple questions in one sentence</li> <li>Interviewing clients in front of staff in institutions</li> </ul>
Recognise that all experts report from their professional perspectives	<ul> <li>Using abstract concepts (e.g. 'rights') without explaining concrete situations</li> <li>Long periods of interviewing without taking breaks</li> </ul>
<ul> <li>Make the environment comfortable for the client</li> <li>Brief supporters that their role is to support communication and not to speak on behalf of the client</li> </ul>	<ul> <li>Answering phone calls during interviews</li> <li>Appearing too friendly or familiar with staff in institutions when meeting the client</li> </ul>
Identify supports which the client chooses when considering remedies	

## 5(E). How can I get my client community-based services so that they can leave the institution?

Access to adequate housing and other community-based services are crucial for people to effectively live in the community. Clients need immediate access to such services in order to leave the institution in practice or in order to continue living in the community and avoid being sent to an institution.

A lack of housing is an easy excuse for local governments to justify continued institutionalisation. An assertive legal strategy is needed in such situations. In addition, lawyers litigating cases should take steps to ensure that their clients have housing in place when they leave an institution.

#### 5(E)(i). Demand housing stock

In addition to human rights-based argumentation on the right to housing, lawyers should consider working with a specialist housing lawyer. It may be useful to identify the relevant government department and service providers, approach them directly setting out the client's requirements and demanding the client's legal entitlements. NGOs can sometimes provide housing or other supports in the short to medium term. Helping the client build a network of support may improve a client's quality of life and, consequently, their constructive participation in long-term litigation.

#### 5(E)(ii). Creatively arrange other supports

As a person with a disability, the client may require specific supports to enable them to live independently, such as assistance in managing their finances, parenting support, housekeeping or to (re-)enter employment. People with multiple disabilities may require physical supports such as a guide-dog or wheelchair, adjustments to their house, physiotherapy, etc. A person with mental health issues may require a community mental health team and access to good quality psychiatrists and mental health nurses.

The effects of institutionalisation can be profound and require considerable (re-)habilitation measures to help the client manage daily tasks which they may never have had the opportunity to learn. Some clients may have been institutionalised as infants and spent their entire lives in an environment where they never cook, clean, go shopping, work, take public transport, open a bank account, buy a mobile phone or even socialise with people in ordinary settings or with people without disabilities. Some may lack skills in parenting, or never have had an intimate relationship. The effects of inhuman or degrading conditions in institutions, sometimes amounting to torture, may require tailored psychological and physical supports to overcome.

Assertive engagement with health and social service authorities or other relevant government departments may be necessary to secure access to specialised services. Where specialist services do not exist it may be appropriate to discuss the need with local social services departments or the Mayor's office. As organs of the State they have duties to provide such services, although they may be unaware of this. In some cases, a complaint may help to get action.

In tandem with broader strategic litigation, an individual application for a specific service can potentially achieve immediate results, depending on the competence of the court or other body petitioned. While it is the responsibility of the State to provide such services and ensure reasonable accommodations, in practice this often does not happen. Lawyers should consider whether it is possible to sue the state for compensation for failure to provide services, for harm caused during institutionalisation and for the return of disability-based benefits (or others, such as employment assistance), a proportion of which may have been paid to the institution during a client's unlawful detention. If successful, this financial remedy will at least allow the client to kick-start their life in the community and potentially to purchase supports that they need.

### 5(F). My client has "litigation fatigue". What should I do?

Litigating human rights cases can be difficult for any client, especially if they have faced years of stigma, discrimination, abuse and silencing of their voices. It is important that lawyers

recognise the impact that these factors can have on a client, and take steps to mitigate the risk that they withdraw their legal claims.

#### 5(F)(i). Strengthen supports

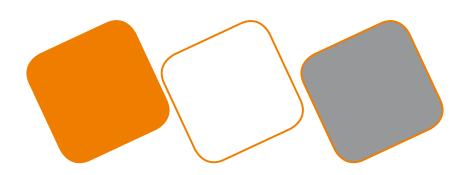
Lawyers should talk to the client and understand their reasons for wanting to withdraw. In MDAC's experience it can be because the lawyer is not communicating properly with the client, that the client does not have enough supports, or because they have lost interest in achieving the outcome of litigation. Whichever motivation the client has, the lawyer needs to respond.

<sup>65</sup> For a definition, see section 4(B)(iv)., above.

If the client is showing signs of being unable to sustain the pressures of litigation, the lawyer should spend additional time with them to find out their reasons – perhaps there is some form of support which they have needed but not received. It may be that they simply need a break from the case, which the lawyer can facilitate. Lawyers should use their creativity to reduce the burden on the client. This could include relying on other witnesses or on written statements rather than asking the client to testify; seeking an adjournment in a court proceeding; or ensuring that the client does not come face-to-face with an abuser.

Some clients find it difficult to be involved in litigation because of their particular impairments. Some clients need more time and explanations to understand the process and their role in it. Some may find explaining their issues to a lawyer and/or testifying in court overwhelming and may get frustrated because they cannot communicate in a manner they would like to.

The lawyer must always be aware of the obligation to provide reasonable accommodations<sup>65</sup> when interviewing and seeking input from the client and by applying to the court for adjustments to the proceedings to ensure their involvement. Applications could include having a support person accompany the client to court, allowing the client to testify via video link or in an informal setting, taking regular breaks during testimony, etc. – all of which can reduce the pressures on the client and facilitate successful litigation. Likewise, during interviews with the client, reasonable accommodations may include some of the same measures as well as arranging meeting times to suit the client, or meeting in the client's space or another comfortable or non-threatening environment, instead of at the lawyer's office.



#### **Appendix 1. Case law**

#### **European Court of Human Rights**

- Anguelova v. Bulgaria, Judgment 13 June 2002, Application No. 38361/97
- Assenov and Others v. Bulgaria, Judgment 28 October 1998, Application No. 24760/94
- Aydin v. Turkey [GC], Judgment 25 September 1997, Application No. 23178/94
- Bureš v. Czech Republic, Judgment 18 October 2012, Application No. 37679/08
- Câmpeanu v. Romania [GC], Judgment 17 July 2014, Application No. 47848/08
- Cordova v. Italy, Judgment 30 January 2003, Application No. 40877/98, ECHR 2003-I
- Fayed v. the United Kingdom, Judgment 21 September 1990, Application No. 17101/90, Series A no. 294-B
- Ilhan v. Turkey, Judgment 27 June 2000, Application No. 22277/93
- Ireland v. the United Kingdom, Judgment 18 January 1978, Application No. 5310/71, Series A no. 25
- Karner v. Austria, Judgment 24 July 2003, Application No. 40016/98
- Kędzior v. Poland, Judgment 16 October 2012, Application No. 45026/07
- Keenan v. the United Kingdom, Judgment 3 April 2001, Application No. 27229/95
- Kudła v. Poland [GC], Judgment 26 October 2000, Application No. 30210/96, ECHR 2000XI.
- Matter v. Slovakia, Judgment 5 July 1999, Application No. 31534/96
- McGlinchey and Others v. the United Kingdom, Judgment 29 April 2003, Application No. 50390/99, ECHR 2003V

- Mihailovs v. Latvia, Judgment of January 2013, Application No. 35939/10
- Mikhaylenko v. Ukraine, Judgment 30 May 2013, Application No. 49069/11
- Nencheva and Others v. Bulgaria, Judgment 18 June 2013, Application No. 48609/06.
- Nevmerzhitsky v. Ukraine, Judgment 5 April 2005, Application No. 54825/00
- P, C & S v. the United Kingdom, Judgment 16 July 2002, Application No. 56547/00
- Ramirez Sanchez v. France [GC], Judgment 4 July 2006, Application No. 59450/00
- Roche v. the United Kingdom [GC], Judgment 19 October 2005, Application No. 32555/96, ECHR 2005-X
- Salontaji-Drobnjak v. Serbia, Judgment 13 October 2009, Application No. 36500/05
- Selmouni v. France [GC], Judgment 28 July 1999, Application No. 25803/94, ECHR 1999-V
- Shtukaturov v. Russia, Judgment 27 March 2008, Application No. 44009/05
- Stanev v. Bulgaria [GC], Judgment 17 January 2012, Application No. 36760/06
- Z.H. v. Hungary, Judgment 8 November 2012, Application No. 28973/11

#### UN Committee on the Elimination of All Forms of Discrimination against Women

Alyne da Silva Pimentel v. Brazil (Communication No. 17/2008)

#### **Inter-American Court of Human Rights**

Ximenes-Lopes v. Brazil, Judgement (IACtHR, 4 July 2006)

Supreme Court of the United States of America' Olmstead v. L.C. 527 U.S. 581 (1999)

#### **Appendix 2. Further Reading**

#### The right to community living

- C. Parker, "Study: Forgotten Europeans forgotten rights: the human rights of persons placed in institutions" (United Nations Office of the High Commissioner for Human Rights, 2011)
- Council of Europe Commissioner for Human Rights, The right of people with disabilities to live independently and be included in the community, Issue Paper (2012)3
- European Network on Independent Living, Defend the right of independent living – how the EU's austerity policy is undermining the lives of people with disabilities. Report from the Hearing in the European Parliament 9 February 2012 (Valencia: 2012)
- European Union Agency for Fundamental Rights (FRA), Choice and control: the right to independent living (Vienna: 2012)
- European Union Agency for Fundamental Rights (FRA), Legal capacity of persons with intellectual disabilities and persons with mental health problems (Vienna: 2013)
- Inclusion International, Inclusive Communities = Stronger Communities: Global Report on Article 19: The Right to Live and Be Included in the Community (London: 2012)
- J. Mansell, "Deinstitutionalisation and community living: progress, problems and priorities", Journal of Intellectual and Development Disability, 31(2) (2006): 65-76
- K. Ericsson, and J. Mansell, "Introduction: Towards deinstitutionalisation" in Deinstitutionalisation and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA, 1996
- L. Clements and C. Parker, The European Union and the Right to Community Living, (Open Society Foundations (OSF), 2012)
- Peter Bartlett, Oliver Lewis and Oliver Thorold, Mental Disability and the European Convention on Human Rights (Netherlands: Martinus Nijhof, 2007)
- R. Townsley, Report: "The implementation of policies supporting independent living for disabled people in Europe: Synthesis report" (ANED, 2010)
- T. Degener, "Disability as a subject of international human rights: law and comparative discrimination law" in The human rights of persons with intellectual disabilities: Different but equal, Gostin, H. S. L., and Koh, H. (Oxford: Oxford University Press, 2003), 151–184
- United Nations Office of the High Commissioner for Human Rights (OHCHR), Getting a Life: Living Independently and Being Included in the Community (New York and Geneva: 2012)

#### **Strategic litigation**

- Center for Strategic Litigations, What is Strategic Litigation?,
  Website at <a href="http://strategiclitigations.org/category/aboutus/whatisstrategiclitigation/">http://strategiclitigations.org/category/aboutus/whatisstrategiclitigation/</a> (last accessed: 24 September)
- D. Creasey, P. Mohen, and B. Schokman, B., Short Guide Strategic Litigation and Its Role in Promoting and Protecting Human Rights (DLA Piper, 2012)
- J.A. Goldston, "Public Interest Litigation in Central and Eastern Europe: Roots, Prospects and Challenges", Human Rights Quarterly, 28 (2) (2006)
- V. Jaichand, "Public Interest Litigation Strategies for Advancing Human Rights in Domestic Systems of Law", SUR International Journal of Human Rights, 1 (2004): 127-142
- K.A. Buchko, E. Rekosh, and V. Terzieva, Pursuing The Public Interest: a Handbook for Legal Professionals and Activists (Public Interest Law Initiative, 2001) 82
- Legal Services Commission, Public Law Project: Guide to Strategic Litigation (London: 2013)
- O. Lewis, "Advancing Legal Capacity Jurisprudence", European Human Rights Law Review, 6 (2011) 700
- P. Reading, "The Importance of Strategic Litigation: the Experience in Britain" (Equality and Human Rights Commission, 2010)
- R.A. Cichowski, The European Court and Civil Society; Litigation, Mobilisation and Governance, (Cambridge: Cambridge University Press, 2007)
- United Nations Entity for Gender Equality and the Empowerment of Women, "Engage in strategic litigation", available at <a href="http://www.endvawnow.org/en/articles/948-engage-in-strategic-litigation.html">http://www.endvawnow.org/en/articles/948-engage-in-strategic-litigation.html</a> (last accessed: 24 September 2014)

#### Notes