

My Future Care Road Map

Planning Tool Guidance Document



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Introduction

This document is a guide to using the *Future Care Road Map* (FCRM) process of planning for the future care of people with an intellectual disability (ID).

The FCRM tool and process was developed to plan for the future care of adults with ID who are living and being cared for in a family context. The tool and process may also translate to other contexts and care situations. The person with ID is a central and active participant at all stages of planning their road map, and they play an active role in its implementation.

This document is intended to guide users through the process of creating a FCRM, and should be used in conjunction with the FCRM Tool (see Appendix 1). The FCRM tool and Guidance Document are the property of the Trinity Centre for Ageing and Intellectual Disability, Trinity College Dublin. Users of the FCRM in conjunction with the Guidance Document are responsible for ensuring compliance with data protection regulations around the collection and use of personal data under the General Data Protection Regulation (GDPR).

Glossary of Terms and Abbreviations

DS	Day Service
FCRM	Future Care Road Map
ID	Intellectual Disability
IL	Independent Living
IRC	Irish Research Council
NGO	Non-Governmental Organisation
TCAID	Trinity Centre for Ageing and Intellectual Disability

Section 1: Overview of the FCRM Planning Process

The FCRM is a future care planning process that was developed by the Trinity Centre for Ageing & Intellectual Disability (TCAID) in Trinity College Dublin. It was developed as part of an action-research pilot study funded by the Irish Research Council (IRC) which developed and implemented a process of future care planning with 12 adults with ID and their family carers in Ireland. The aim of the study was to create a tool and process to enhance future care planning for adults with ID and their family carers. By doing so we ultimately wanted to provide clarity for people with ID about their future, whilst helping to alleviate the anxiety that ageing carers in particular have about future care.

The purpose of the FCRM is to enable individuals with ID, their primary carer and other family members involved in providing care or support, to engage in the process of planning for the future. Where people are also supported by formal support services, it is a good idea for service staff (e.g. keyworkers and social workers) to contribute to the process of outlining current and future support. Having formal services involved may also help to corroborate information or opinions, and to fill in any gaps when gathering information for the plan.

To proceed with the FCRM process, it is essential to have participation from the care recipient and the primary carer. Participation of others, including other family members, friends and anybody else involved in providing care or support to the individual with ID, is welcome as it provides a broader base of knowledge for the plan and support for the future. While not essential, families may find it useful to have a facilitator to guide the process.

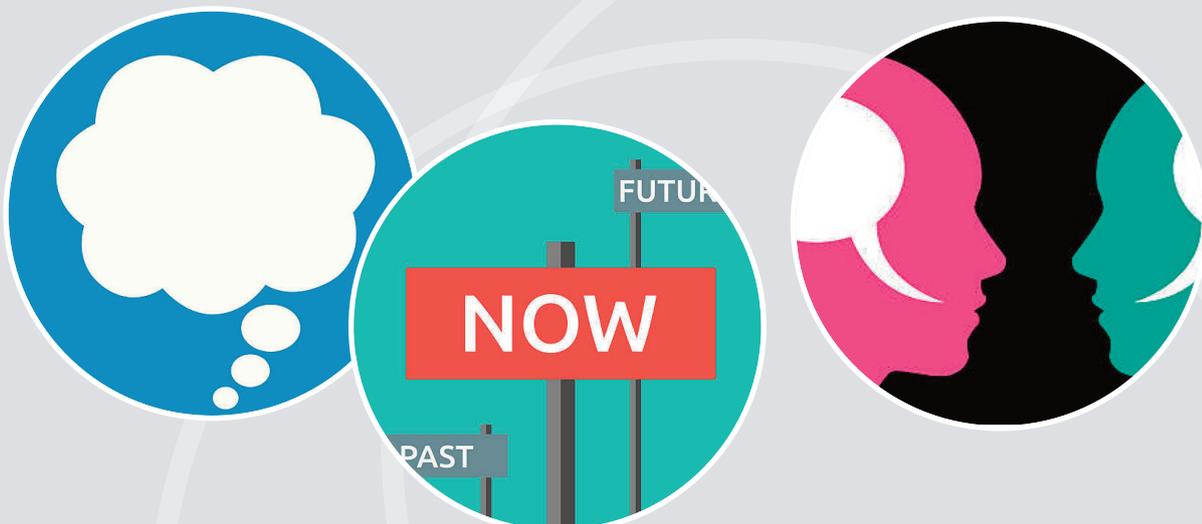
FCRM Tool

The FCRM Tool is described in detail in Section 2 of this Guidance Document, and included in Appendix 1. The Tool was developed following a review of the research literature, and the broad overall approach to planning utilised here was influenced by the quality of life approach used by O'Grady Reilly and Conliffe (2002). The key planning domains in the FCRM tool include:

- (i) Interests and activities
- (ii) Family, friends and others
- (iii) Work, training and day activity
- (iv) Living arrangements
- (v) Care and support arrangements
- (vi) Legal arrangements
- (vii) Financial arrangements

Timeframe

The duration of the planning process will vary depending on the circumstances of each individual case. It may be influenced by the recruitment period, availability of each party to contribute, data collection and analysis, and development of the plan itself including feedback loops. The average duration during the pilot study was approximately 15 weeks from start to finish.



Process

Figure 1 below provides an overview of the FCRM process. Additional details on the different stages of the process are provided in subsequent sections of this Guidance Document.

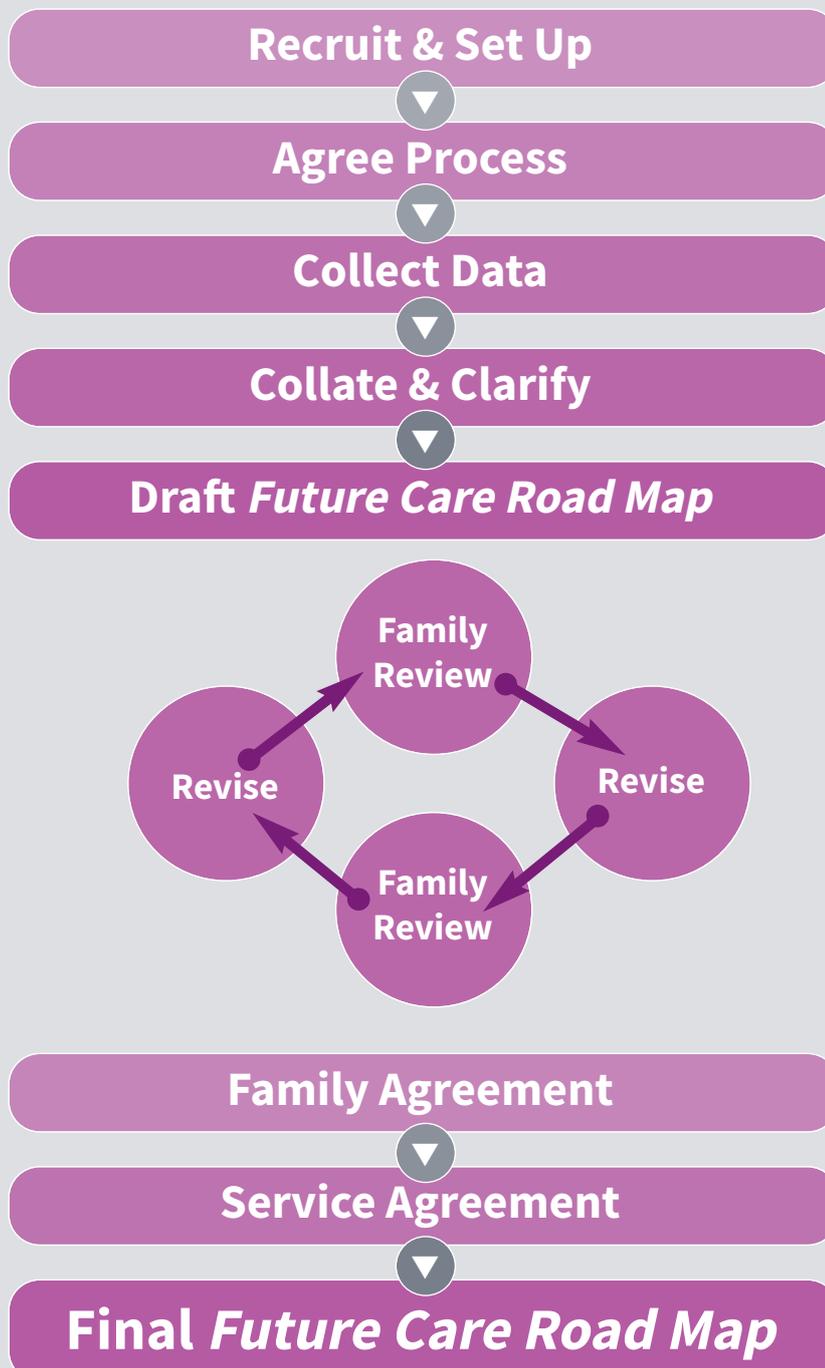


Figure 1:
Overview of the
FCRM Process

Section 2: The FCRM Planning Process

As outlined in Figure 1 above, there are nine separate stages in the FCRM planning process.

Stage 1: Recruitment and Set-up

The first step in the FCRM process is to recruit participants for the planning process. As noted above, participation of the **care recipient** and the **primary carer** are essential to proceed with the FCRM process. It is possible that the process will have been initiated by one or both of these so they are likely to be willing participants.

However, where the process is initiated by another party then it will be important to provide the required level of accessible information to obtain informed consent from the care recipient and carer. This means that it may be necessary to develop an information booklet and consent form for the process – although this is probably unnecessary where families take on the planning process themselves in a private capacity.

Participation by others is also encouraged as it provides a broader base of knowledge for the plan and support for the future. These include **other family** members, **friends** and anybody else involved in providing care or support to the individual with ID, including mainstream or specialist **support services**.

Essential Personnel

- Individual with ID being cared for in the family home
- Primary family carer

Additional Personnel

- Facilitator
- Other family members, friends, advocates or others
- Formal support services who know the individual with ID (e.g. keyworker or social worker)

It is possible that other family members may be recruited later in the process – for example when early drafts of the FCRM are ready they may be shared with individuals who have been identified in the plan as important for certain aspects of support. Face-to-face input is not the only way to involve participants in the FCRM process. During the pilot study, a number of family members and support staff made important contributions to the process by email, phone and text.

As well as this, the potential for indirect as well as direct input to the process should also be facilitated. During the pilot study, it was common for family members other than the primary carer (e.g. the father or a sibling) and support staff other than a keyworker (e.g. a day service manager or social worker) to contribute indirectly to the process. This was usually done by communicating feedback or confirming support for draft plans to the facilitator through a direct participant (e.g. the primary carer or keyworker).

Facilitator Role

In the FCRM pilot study, a **facilitator** was used to oversee all stages of the planning process for families, from recruitment right through to completion of the plan. While having a facilitator is not essential to the FCRM process, families involved in the pilot study reported that it was important and very useful for them to have a facilitator to guide the process.

A facilitator may support the process in a number of ways, including:

- Being external to both the family and support services, he/she may engage in and guide the process more objectively;
- Engage unilaterally with the care recipient, carer and service providers in the data collection process;
- Act as a sounding board for all participants in the process, thereby minimising the risk of creating conflict amongst different parties;
- Use their knowledge of services and/or the local community to identify options for the future planning process;
- Bring a degree of creativity regarding solutions and options for future care/support that those close to the individual or family may not see;
- Be more familiar with the overall mechanics and dynamics of the planning process and, therefore, be better placed to manage the process.

If an external facilitator is not used in the process, then someone else within the process will need to take on the role of organising and managing the process, as there is a clear need for this role, regardless of who takes it on. In the stages that follow, we will refer to specific facilitator tasks or functions, which may either apply to an external facilitator (as recommended) or to someone assuming that role.

Stage 2: Agreeing the Process

Once the personnel have been recruited to the FCRM process, the next step is for all parties to agree on what needs to be done and by whom. This is a process of clearly establishing the key responsibilities and expectations of each person involved. It will be the role of the facilitator (or alternative) to agree these aspects of the process with each participant.

At this stage, the facilitator should also identify the availability of participants for initial data collection and broadly agree with all parties how long he/she expects the planning process to last.

Stage 3: Data Collection

The data collection stage aims to gather sufficient information about the care recipient and the caring context to establish the future wishes of the care recipient and the resources (i.e. people, services or things) that will support those wishes.

Participants

Data collection will involve interviews with the key FCRM participants – namely:

- The care recipient
- The carer
- Service provider
- Other family members and friends (if applicable)

Where possible, interviews with these participants should be carried out separately. This will help to yield information from each party without influence by another. In particular, it may enable the care recipient and carer to speak more freely about their wishes and concerns about the future. It will also provide triangulation of data where potentially uncertain information may be corroborated by other participants.

However, it may not be possible to conduct each interview separately. For example, the care recipient may have cognitive, communication or other challenges that require a supported interview. In such situations, it is preferable that the care recipient is supported in his/her interview by someone other than the primary carer or another family member. Ideally, someone who knows the person well and with whom the care recipient is comfortable, would support them in their interview. In many cases, this is likely to be a keyworker but may also be a friend or advocate.

Interview schedule

The proposed interview schedule for the FCRM process is outlined in Table 1 below. This outlines the seven planning themes (or topics that will be planned for) that will form the structure of the interview with each participant.

Table 1: FCRM Interview Schedule

Planning Theme	Current Situation / Arrangements	Current Supports for These	Future Wishes / Arrangements	Future Supports for These
1. Interests & activities				
2. Family, friends & others				
3. Work, training & day activity				
4. Living arrangements				
5. Care & support arrangements				
6. Legal arrangements				
7. Financial arrangements				

As well as providing a more holistic approach to planning through the inclusion of social aspects of the care recipient's life, the proposed sequence also allows for easier conversations about interests and friends before getting into potentially more difficult discussions around future living and caring arrangements.

Flexibility

A large degree of flexibility will be needed when using the above proposed interview schedule. Exceptions and adaptations may be needed in some circumstances, such as:

- Not all families will wish to plan for all of the areas identified;
- The care recipient may not have the cognitive ability to discuss all of these topics (particularly with regard to conceptualising an abstract future and projecting future wishes);
- Not all participants will have information on all of these topics (e.g. some keyworkers may only have information regarding interests, friends and day activities);
- Not all participants will want to discuss all of these topics.

Given these potential exceptions, it is important that the process is kept as flexible as possible to facilitate the involvement of key participants.

Probing in interviews

Participants should be asked to be as specific as they can when outlining future plans and intentions, and in identifying the resources (i.e. people or things) that will enable those future plans/intentions. This will apply most directly to care recipients and carers.

As such, it may be necessary during interviews (or perhaps in follow-up) to probe care recipients and carers for specifics with regard to how future plans will be supported and who or what will be responsible for these plans. It may be that, at the time of interview, neither the care recipient nor the carer know or fully know how future plans or wishes will be supported. However, these issues may be explored later in the process with the range of possible options identified by the facilitator based the full range of information.

Part of this process will include probing for contingency planning for certain aspects of the plan including future living, caring, legal and financial arrangements. This is a ‘safety net’ element to the plan which aims to ensure a Plan B is put in place to support future arrangements, in a scenario where current support is no longer available. For example, caring arrangements may be for the current carer to continue caring into the future. However, a contingency plan for caring arrangements should identify a person or service that will take over the responsibility for care should the carer be unable to continue caring. It may not be possible to identify a contingency plan for all circumstances; but where it is possible to identify a contingency measure, it should have the prior agreement of the named person before being finalised in the plan.

Probing may be used to identify contingency plans for these areas. With some participants, and care recipients in particular, discussion of future plans and contingency planning may be very delicate, so caution will be required by the facilitator not to cause upset or anxiety (see below also).

It may not be possible, at the time of interview, for a carer or care recipient to identify future supports for specific future plans. However, this is something that must be resolved in the FCRM process. Nothing should go into the final plan that does not have the backing of a named support and a person responsible for delivering that support (with the person named signing their approval).



Supporting care recipients

When care recipients with ID are being interviewed, it may be necessary to tailor the process to suit individual circumstances or adapt the interview schedule to suit their ability. Consultation and advance planning will identify appropriate adaptations to the process. This may include:

- **Making the interview process accessible:** Building on the accessible Information Booklet that explains the purpose of the FCRM process to care recipients with ID, facilitators should:
 - Plan for accessibility in advance through consultation with participants regarding the individual’s ability to participate;
 - Base communication on the individual’s preferred methods and style, using accessible materials and communication tools as appropriate;
 - Use accessible language throughout the process to maximise participation;
- **Focusing on the present:** Some care recipients may have difficulty conceptualising the future; in these cases, it is important to focus on the present – to identify things they do now and current arrangements, the support they receive for these, and the things that they like and dislike (which may, in some cases, be extrapolated to the future or, at least, inform future planning);
- **Making the future relatable:** Some care recipients may have some understanding of future concepts, but will benefit from making the future more relatable and less abstract; the correct language can make a big difference in this regard, with simple phrases such as “when you’re a bit older” or “in a few years’ time” making the future more understandable;
- **Managing sensitive topics:** To avoid undue harm to the care recipient, it may be necessary to consider discussion of particular issues, which may be very sensitive topics (e.g. potential illness or death of parent in the future) or topics/scenarios that may cause undue anxiety (e.g. potential move of residence in the future);

- Emotional support: It is good practice, when interviewing people about potentially sensitive topics, to identify in advance a process and resources for supporting individuals should they become upset during the interview; this may include advance warning in the accessible Information Booklet and, again, verbally at the start of an interview; identifying supportive individuals who may be with the interviewee during the interview or close by if needed; or details of relevant professional support services that the interviewee may be referred to.

Recording data

In the pilot study, the approach used to record data was for the facilitator to write detailed field notes during interviews. This approach was unobtrusive and allowed the interviewee to be more at ease than they may be if an audio or video recording was made. The method was found to work quite well since the interview schedule, though relatively structured, lends itself to a conversational approach more in keeping with the desired tone for rapport building. Additional reflective notes and follow-up conversations were also used to supplement field notes.

The facilitator in the pilot study was also an experienced interviewer, so this may be an important skillset to consider when appointing a facilitator.



Stage 4: Collating & Clarifying Information

Field notes should be written up soon after each interview, and supplemented with additional reflections, observations and fleshing-out of notes or comments about the interviewees' demeanour, non-verbal communication or circumstances of the interview.

In typical circumstances, there will be three sources of data providing information for the thematic planning areas in the FCRM: the care recipient; the carer with other family if relevant; and the service provider. The data collection process will have collected information in a quite structured way and, therefore, the collation of data should be relatively straightforward in accordance with the seven planning themes.

Where there is disagreement in the information provided by individual participants, the presence of three perspectives should allow for corroboration between at least two parties in most cases. However, if this is not possible, it may be necessary to do some follow-up with one or more of the participants. Where there is uncertainty or vagueness in the data, a similar exercise may be required. The aim in either case should be to corroborate all key data elements amongst participants. For greater efficiency, points of disagreement and uncertainty should be collated for clarification with the relevant participant(s) at the same time.

A distinction should be drawn, however, between points of factual information and the stated opinion, preference or wishes of the care recipient. Disagreement on points of factual information should be corroborated as suggested; however, the personal views of the care recipient regarding their preferences or wishes for the future should be respected, even where they may be contradicted by other participants.

Stage 5: Drafting the Plan

Once the dataset has been collated and clarified, the next step is to begin drafting the FCRM using the template tool provided. At this stage, the individual participants may still be uncertain as to the precise plans under some of the themes. It may be the facilitator's role to now contribute their knowledge or experience to identifying options available to the care recipient and carer. Given that some uncertainty may remain at this stage in the process, this initial plan may be considered as simply the next step in the process rather than an almost-final plan. It is something to bring forward to the next stage of the process for consideration, discussion and agreement by the family.

Caring capacities

It is also at this stage when we must consider one of the most fundamental aspects of the FCRM process. We must recognise that, while we aim for the FCRM process to be as inclusive and person-centred as possible, there are other dynamics which underlie the future possibilities that are open to the care recipient. These relate to the **capacity** of named supports to provide the support required.

Whilst the personal wishes of the care recipient are the primary source to consider when determining future plans in each of the seven areas, the FCRM process must also be based on how realistically those wishes may be supported. In each instance, named supports must agree to undertake the supportive action required in the future. If it is not possible to secure this support, then an alternative option to the unsupported wish/plan should be devised and agreed. This will mostly arise as an issue with regard to planning for future caring arrangements and living arrangements which, for many individuals and families, are the core of the future planning process. These arrangements are also the ones which typically require most support and often go hand-in-hand when being considered. Future wishes in the other thematic areas tend to be more easily accommodated.

The pilot study confirmed that the capacities of three key actors are critical in determining the plans agreed in the FCRM. These are:

- The caring capacity of the care recipient with ID
- The caring capacity of the family
- The caring capacity of formal support services

It emerged in the pilot that due consideration should be given to the potential for the care recipient to enhance their own capacity for self-care in the future, as a potential alternative or supplement to family and service supports. This may entail, for example, planning for the assessment and delivery of a programme of independent living (IL) skills training for the care recipient as a way of increasing his/her options should their current care be disrupted in the future. This may occur where support by the current primary carer is no longer available but the care recipient may be able to continue living in their current home through a combination of their own enhanced IL skills plus the addition of formal services (e.g. Home Help) and/or periodic input from other family.

Structure of the FCRM

The seven thematic areas for planning in the FCRM tool, in line with the data collection interview schedule, are:

- (i) Interests and activities
- (ii) Family, friends and others
- (iii) Work, training and day activity
- (iv) Living arrangements
- (v) Care and support arrangements
- (vi) Legal arrangements
- (vii) Financial arrangements

The tool assigns a separate page for each theme and, in the pilot, it was possible to keep to one page for each theme. This made for a clearer plan, the logic of which participants found relatively easy to follow.

Within each of these seven themes, there are four columns that outline:

- Statement of a future plan/intention
- The types of supports required to achieve the stated future plan/intention
- The action(s) required to achieve the future plan/intention
- The person(s) responsible for delivering each action

Any person named as responsible for delivering on a specific action will be added to the list of 'Named Supports' on the front of the FCRM and will be asked to sign up at the end to provide the support identified.

The following sections will illustrate examples of how future plans may be stated and supported under each theme of the FCRM.

1. Interests & Activities			
Statement of Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
<p>Pat currently enjoys many interests and activities; he would like to continue these in the future.</p> <p>At home/with his family:</p> <ul style="list-style-type: none"> ✓ Cooking with mum ✓ Going shopping ✓ Etc. <p>At Day Service (DS):</p> <ul style="list-style-type: none"> ✓ Swimming ✓ Literacy Class ✓ Going for walks around town ✓ Etc. 	<p>Pat needs someone to support him to take part in all activities outside the home, including support with transport and travel.</p> <p>Support to attend Day Service.</p> <p>Support and supervision with activities at Day Service and for activities outside the centre and around town.</p>	1. Continue to support Pat to cook at home.	■ Mum
		2. Continue to support Pat to go shopping.	■ Mum and Dad ■ Sister
		3. Continue to support Pat with transport to attend DS.	■ Service/ Keyworker Name
		4. Continue to support Pat's activities in and outside of DS.	■ Service/ Keyworker Name
<p>Pat sometimes joins in Pilates at the DS on Fridays: and would like to do more in the future.</p> <p>The instructor, Sue, will develop a one-to-one programme for Pat, as is his preference.</p>	<p>Develop One-to-one Pilates programme for Pat.</p> <p>Support him during weekly sessions at DS.</p>	5. Develop Pilates programme for Pat.	■ Service/Sue
		6. Support Pat during weekly Pilates session.	

Figure 2:
Example of Planning for 'Interests & Activities'

‘Interests & Activities’ theme will plan for the social and leisure interests or activities that the care recipient wishes to plan for in the future (see Figure 2). The interests and activities that the care recipient currently enjoys and wishes to continue in the future will normally be identified as the first plan/intention for the future under this theme.

When this is the case, then existing support is likely to simply continue into the future – there is no need to make changes where these are not necessary or wanted by the care recipient.

For every future plan/intention there must be identified actions to deliver these, and a corresponding person or persons named as responsible for delivering on each action.

This remains the case for future plans/intentions that simply involve a continuation of current arrangements.

In addition to current interests and activities, care recipients may wish to undertake new activities in the future. Each of these should be laid out individually as separate plans with corresponding supports, actions and people responsible.

2. Family, Friends & Others			
Statement of Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
<p>The most important people in Anne’s life now will continue to be important in the future.</p> <ul style="list-style-type: none"> ■ Anne’s Family <ul style="list-style-type: none"> • Mother Bernie • Father Jack • Sister Jane (and Pat and Lucy) ■ Anne’s friends: <ul style="list-style-type: none"> • Maggie and Catherine • Liz at the DS ■ Anne’s keyworker Sandra at [Service] 	<p>Anne lives with her parents so doesn’t need any particular support to maintain these relationships.</p> <p>Anne needs support to maintain some of her other relationships:</p> <ul style="list-style-type: none"> ■ Sister Jane to visit Anne. ■ Support to visit her friends Maggie and Catherine. ■ Transport to attend DS to see her friends there. 	1. Continue to visit Anne in the family home.	■ Jane and family
		2. Continue to support Anne to visit and see her friends Maggie and Catherine	■ Bernie and Jack
		3. Continue to support Anne with transport to attend DS	■ Service / Sandra
<p>In the future, Anne would like to meet more friends her age in her local area. She will develop a plan of social activities to meet new people.</p>	<p>Support to identify social opportunities.</p> <p>Support to arrange new social activities and supports required.</p>	4. Identify social opportunities.	■ Anne
		5. Identify supports needed by.	■ Service / Keyworker name
		6. Agree plan of social activities with supports.	■ Carer name / Family

Figure 3:
Example of Planning for 'Family, Friends & Others'

3. Work, Training & Day Activity

Statement of Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
<p>Helen attends the [Service] day centre every Monday to Friday.</p> <p>At DS, Helen does swimming, jigsaws, yoga, art, literacy skills, and goes out in town, shows and trips to the city.</p> <p>Helen is very happy at DS and would like to continue going there in the future.</p>	<p>Helen needs support with transport to travel to/from DS and related activities.</p> <p>Helen also needs support with activities at DS.</p>	1. Continue to support Helen to with transport to/from DS every day.	■ Service / Keyworker name
		2. Continue to support Helen's activities at DS.	■ Service / Keyworker name
<p>Helen does voluntary work for an hour every week in the charity shop in town.</p> <p>This is something that Helen enjoys and she wants to continue working there in the future.</p>	<p>Helen needs support travelling to and from her work in the charity shop each week.</p> <p>Helen also needs support and supervision in doing her work at the charity shop.</p>	3. Continue to support Helen travelling to work in the charity shop.	■ Service / Keyworker name
		4. Continue to support Helen in her work at the charity shop.	■ Service / Keyworker name

Figure 4:
Example of Planning for 'Work, Training & Day Activity'

The 'Work, Training & Day Activity' theme plans for any occupational or day activity that the care recipient engages in; this includes employment, training, day services or volunteer work (Figure 4).

It may be the case that a care recipient is very happy doing what he/she currently does; if that is the case, then actions and supports will most likely simply continue as present.

However, this planning process may be an opportunity for the care recipient to express an interest in other activity, and so may also identify desired new work, training or day services for the future.

Where a new job/plan is identified, it is important that the plan remains realistic. It should outline achievable steps towards the future goal, rather than simply identifying the end. For example, if a care recipient identifies the goal of working in paid employment in the future, this may be broken down into smaller steps that work towards that end.

4. Living Arrangements

Statement of Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
Susan lives in her family home with her mum Mary and dad William. Susan is very happy living at home with her parents, and wishes to continue living there in the future.	Susan helps out with some things at home, including... [list]. Susan needs support at home with other including personal care, cooking, cleaning and supervision.	1. Continue to support Susan to live at home.	■ Mary and William
Susan goes to respite in town four times a year for a 3 days at a time. Susan enjoys going to respite and wants to continue going in future.	Living supports as outlined above when staying in the respite house.	2. Continue to support Susan to stay at the respite house in town.	■ Service / Keyworker name
In future, when her parents are unable to support Susan at home, she will move in with her sister Lisa and Dave in their home. Brother Liam and Nora will provide extra support then with regular weekend stays for Susan at their family home.	Living supports as outlined above.	3. Agree to live with Susan in the future when required.	■ Lisa and Dave
		4. Provide living supports to Susan when living together in the future.	■ Lisa and Dave
		5. Support Susan to stay over for weekends at their home in the future.	■ Liam and Nora

Figure 5:
Example of Planning for ‘Living Arrangements’

This may include: support from their keyworker in finding a job coach or service; working on building a CV; training programmes; support to identify suitable positions; and support interview skills and applying for positions identified. Regardless of the goal and the steps to get there, each action should be supported by a named support person. Depending on the age of the care recipient, this may also be an opportunity to plan for retirement, or stepping back and slowing down with some of the work / day activities they currently engage in.

The ‘Living Arrangements’ theme outlines plans for the future housing or accommodation needs of the care recipient and the supports required for those situations (Figure 5). Identifying future living arrangements is often the core issue for families engaged in future planning (alongside future care).

Identify all living situations which the care recipient currently uses here, as these will normally be continued in the future. This should outline all living contexts, including:

- Main residence
- Secondary residence (if applicable – e.g. sometimes care recipients divide their time between living with different family members)
- Periodic or occasional stays with other family members or friends (informal)
- Respite services (formal)

Planning for living arrangements may take a short, medium and long-term view. They should be guided, first and foremost, by the care recipients wishes for the future but plans also need to be grounded in an awareness of capacities to support those wishes.

Short-term planning may simply outline a continuation of current living arrangements for what may be a defined or undefined period, depending on the circumstances. Medium-term planning may be required if a particular transition point is identified (e.g. transfer to supported accommodation services).

Agreeing long-term living arrangements may include an indefinite continuation of the current situation. However, in these and all other cases, it is highly recommended that a **contingency plan** for what happens when current arrangements and/or supports are disrupted and no longer available is agreed and stated in the FCRM.

Contingency planning will require consideration of the care recipient's wishes alongside the capacities of different parties to support those wishes – i.e. the capacity of the person, the capacity of the family network and the capacity of formal support services.

Options for future living will be identified in this way (Preferences + Capacities = Options).

Contingency plans may include:

- Agreement that another person (e.g. second parent or a sibling) will take over the role as primary carer when required;
- Agreement that another person will take over the primary carer role with additional supports (e.g. other family members stepping up their input through added support including periodic respite, increased formal support services, and/or increased independence through improved IL skills by the care recipient);
- Where the care recipient has good potential for independence, a contingency plan may involve planning to improve his/her IL skills with a view to independent or semi-independent living options in the future;
- Application for formal supported accommodation services (through the HSE and/or an existing disability service provider);
- Contingency plans may creatively utilise a combination of the above options to secure the continued long-term living arrangements of care recipients.

5. Care & Support Arrangements			
Statement of Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
Carol's main carer is her mother Mary, with support from her dad Henry. Together they support Carol to live at home. Carol is very happy with these support arrangements and would like to continue in future.	Support at home with cooking, cleaning and some personal care. Support managing money including DA, banking, budgeting... Support to manage health including medication and appointments...	1. Continue to support Carol as her main carer.	■ Mary (with support from Henry)
Carol goes to respite every 2 months, at the [Service] house in Town. Carol enjoys going to respite will continue to go there in the future.	Support to attend respite in Town.	2. Continue to support Carol's respite stays in Town.	■ Service / Keyworker / Social Worker
If her mother is unable to continue as Carol's main carer in the future, her sister Elaine take over this role with additional support from Kevin.	Continued support as above, taking over main carer role.	3. Agree to take over role as Carol's main carer when required.	■ Elaine (with support from Kevin)

Figure 6:
Example of Planning for 'Care & Support Arrangements'

The ‘Care & Support Arrangements’ theme will outline how the care recipient’s care and support needs will be met in the future (Figure 6).

Consideration of future care and support goes hand-in-hand with future living arrangements, as available caring capacity will often determine the future living options available to the care recipient. As such, many of the points made under the previous theme will also apply here.

As with living arrangements, a **contingency plan** should be identified for a time when continued current support may no longer be available. It should also identify responsibility for care in the different living arrangements the care recipient currently has (e.g. in respite, or when staying over with other family).

This theme will summarise the care recipient’s needs and how these are met. It will include any important health needs or issues for the care recipient. These may be outlined at a high level (i.e. summarising health needs) or be more specific, if desired.

Given the broad context of the FCRM, it is recommend that health needs are outlined in a high-level manner, summarising the types of care/support required but without getting bogged down in too much detail (e.g. “support managing health including medication for epilepsy and anxiety and making/keeping appointments”).

Note: A key assumption underlying the FCRM in general is that future planning assumes no significant change in the care recipient’s health, disability status or associated care needs. Where a significant change occurs in this regard, with an impact on care needs, then plans may need to be revisited.

6. Legal Arrangements			
Statement of Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
Rory's dad Arthur is also his Next of Kin or Legal Guardian, to assist with official or legal matters. Rory is happy to continue this arrangement in the future.	As Next of Kin, support Rory with any legal or official matters that arise, such as forms and documents.	1. Continue in role as Next of Kin for Rory.	■ Arthur
Rory's sister Fiona will take over as Next of Kin if Arthur is unable to continue in this role in the future.	Provide Next of Kin support, as above, in the future if Arthur is unable to continue in this role.	2. Take over the role of Next of Kin to Rory when needed.	■ Fiona
Fiona will inherit the family house but Rory will have a right to continue living in his home for as long as he wishes.	Support of Rory's right to continue living in the family home for the rest of his life.	3. Support Rory's right to continue living in the family home as long as he wishes.	■ Fiona

Figure 7:
Example of Planning for 'Legal Arrangements'

The 'Legal Arrangements' theme will include plans related to any legal or official matters that affect the care recipient (Figure 7). In most cases, this will include future plans/intentions regarding the care recipient's next of kin or legal guardian; or the person who supports the care recipient with matters of an official or legal nature – from passport applications to estate planning.

It is up to each individual to decide how far they wish to go in planning for legal arrangements. At a minimum, however, it is advised to identify future next of kin/legal guardian support. This often goes hand-in-hand with future care arrangements and, in many cases, the short-to-medium future will simply entail a continuation of support by the current primary carer. However, it is recommended that a contingency plan is created for when that support may no longer be available in the long-term.

Other specific legal matters may also be included in the FCRM, depending on individual circumstances. This may include estate planning for the care recipient or rights and entitlements to a family home now or in the future after parents have passed away.

Depending on the wishes of the care recipient and other family (often parents), planning around future housing rights may be kept informal, as agreed between family members. Others may wish to plan for the right to be made legally binding. The FCRM may, therefore, identify plans for family discussions and/or employment of a professional to draw up a legal agreement.

Alternatively, estate matters and house ownership may not be something a family wishes to get into or may not be something they can resolve within the scope of the FCRM. As such, families may agree/plan to discuss these matters at a later date.

Where someone other than the care recipient is due to inherit the family home, and the care recipient wishes to continue living there in the future, it is preferable for the care recipient and carer to include an agreement around future housing rights.

7. Financial Arrangements			
Statement of Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
Peter's source of income is his Disability Allowance (DA) and wages from his part-time job. Peter's mum Theresa supports him with managing his money. Peter is happy with this arrangement and wishes to continue in the future.	Support Peter with managing his finances and money matters, including day-to-day spending, budgeting, banking and savings.	1. Continue to provide current financial support for Peter.	■ Theresa
If Theresa is unable to continue in this role in the future, Peter would like his brother Colin to take over this role.	Provide financial support to Peter in the future if Theresa is unable to continue in this role.	2. Take over the role of providing financial support to Peter when needed.	■ Colin
Peter would like to learn how to manage his finances more himself in the future. He will undertake finance and budgeting training to improve these skills.	Support to identify suitable training.	3. Discuss skills Peter wishes to learn. 4. Identify suitable training course for Peter.	■ Peter ■ Service / Keyworker name ■ Service / Keyworker name

Figure 8:
Example of Planning for 'Financial Arrangements'

The ‘Financial Arrangements’ theme outlines plans for the future needs and supports of the care recipient with regard to finance and money (Figure 8). FCRM planning within this theme may include information about how the care recipient sustains him/herself financially and the types of support he/she needs to manage financial and money matters.

As with other themes, planning here should think about the immediate future – which often will entail a continuation of current support – but also plan for the longer-term future.

A contingency plan, in line with planning in other themes, should be identified for a time when continued current support may no longer be available, including the name of the person who has agreed to take over this aspect of support.

Stage 6: Family Review & Revision

With a first draft of the FCRM now prepared, the next step involves a process of **review** by the family (including care recipient, carer and others named as supports in the plan) and **revision** by the facilitator. This may go through a number of iterations depending on the circumstances and number of family supporters named in the FCRM.

Usually this process should centrally involve the care recipient and carer. Where possible, it is recommended that the draft plan is presented to the care recipient, carer and other interested family members by the facilitator. This will facilitate a clearer understanding of the layout, structure and content of the plan, and allow key participants the opportunity for questions.

Depending on how the future options identified within the FCRM align with the stated wishes and preferences of the care recipient (particularly regarding future living and caring arrangements), there may need to be a careful process of individual review with the carer and named future supports to confirm capacity, before presenting the viable/feasible options to the care recipient.

As such, a flexible approach to the FCRM process is encouraged, with a view to reaching agreement that the care recipient and others are happy with. This may involve unilateral discussions with the carer and other key supporters (e.g. those identified as contingency future carers) in a process of working through the care recipient's preferences and the capacities to support them, in order to identify available future options.

Any potentially difficult issues will have been flagged in the process to this point – initially in the data collection phase and then through further follow-up and review with participants. So it may be a case of the facilitator negotiating an agreed plan that everyone can sign up to.

There may even be situations, as happened in the pilot, where the primary carer(s) (where two parents are involved) does not wish for the FCRM to be made known to the care recipient; this may happen for a couple of reasons:

1. The carer(s) may indicate that the care recipient does not have a sufficient concept of the future or the planning process to understand the FCRM that is presented to them (this may be supported from the facilitator's interactions with and observations of the care recipient); or
2. The carer(s) may indicate that presenting future plans and especially contingency plans to the care recipient may cause unnecessary anxiety and lead them to think that they are being forced to move house or change their current situation in some way.

Given these scenarios, we must weigh up our aims of being inclusive and person-centred with respecting the genuine and well-grounded fears that carers have based on their intimate knowledge of their loved ones. It is possible that parents or other carers are simply being over-protective. Where their fears and views are contradicted to a reasonable extent by other participants and the facilitator's own interactions with the care recipient, then this may be discussed further with the carer(s).

The family review process will also require input and/or agreement of all named family supporters in the FCRM, although this may take place at a different time to the core participants. Indirect input and agreement from named family supporters may be facilitated where individuals are unable to participate directly in the process – for example, other family members may receive a copy of the draft plan to review and pass on their agreement to the facilitator via the carer or care recipient.

Stage 7: Family Agreement

Following the iterative process of family review and revision, the process will have reached a stage where a draft FCRM is agreed by the care recipient, carer and other family supporters.

This should be grounded in a reasonable expectation that any additional support required, such as those provided by formal support services, will be available. Plans agreed by family should not be based on wishful thinking or 'ideal case' scenarios of service provision. The current reality is that very little, if any, additional resources are likely to be available from the HSE or other formal support services including NGO disability providers.

Stage 8: Service Agreement

With plans agreed by the family, the draft FCRM should next be presented to formal support services for their agreement and support of the plan. This may not be necessary if no formal services supporting the care recipient.

However, in most cases, care recipients are supported by formal services. So, as with all named supporters in the plan, any staff member named as a support to specific plans and actions should be consulted for their agreement.

Keyworkers and social workers will usually be named against specific plans/actions but others, including service managers or respite staff, may also be named.

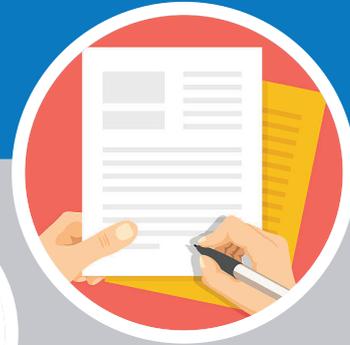
All of those named in the FCRM should sign off on the plan. If they are unwilling or unable to sign up to provide the support then the plan will need to be revised by either changing the plans in question or by finding an alternative supporter.

Stage 9: Finalising the Plan

Once agreement and support by the family and service providers is secured, the FCRM may be finalised and presented to the care recipient. The final outcome of the process is that the care recipient will have a plan for their future that they are happy with, and which is supported by the important people in their lives.

The final step in the process is for the care recipient to sign the FCRM in order to take ownership of it; and to invite all of the other named supporters in the plan to sign up, in an agreement to provide the support identified in the plan (see Figure 9).

My Future Care Road Map



Attach a picture
of yourself here

This is my **Future Care Road Map**.

It outlines the things that I want to do in the future and the people who will support me to do them.

It includes my interests and activities, the people in my life, my work and day activity, where I will live, and who will support me when I am older.

Signed: _____

Date: _____

Figure 9: Signing up to the FCRM

Section 3: Important Considerations

There are a number of general issues that are important to keep in mind when undertaking the FCRM process. These include:

- The FCRM process will be bound by limited time, which should be agreed by participants at the outset, rather than left open-ended;
- The process is also bound by existing resources, and no presumption of additional resources to support future plans should be made;
- Given these practical restrictions of time and resources, the FCRM will only be able to achieve so much and should not be expected to achieve the impossible;
- It should be made clear to families recruited to engage in the FCRM process that no additional services will be provided to them as a direct result of the FCRM;
- The process should be underpinned by inclusive, person-centred approaches which use the care recipient's wishes and preferences as the starting point;
- The FCRM should also be based, however, on what may be realistically achieved;
- The process must weigh up individual wishes against the capacity (of the individual, family or services) to support those wishes;
- Where the capacity does not exist to support the individual wishes or first preferences of the care recipient, alternative options should be negotiated with him/her and other participants;
- If any difficult issues arise that may not be resolved within the timeframe of the FCRM process, these should be parked and noted for further review in the future;
- The facilitator should ensure that focus is maintained on the FCRM objectives and outcomes, and that the process does not become side-tracked with other issues;
- The FCRM process should be flexible enough to adapt to individual family circumstances;
- The FCRM is not legally binding - it is primarily an agreement amongst family;
- The FCRM is not set in stone – it may change or be reviewed at any stage in the future.

References

O'Grady Reilly, K. & Conliffe, C. (2002) Facilitating future planning for ageing adults with intellectual disabilities using a planning tool that incorporates quality of life domains. *Journal of Gerontological Social Work*, 37, 105-119.



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Signed: _____

Date: _____

Planning Tool Guidance Document

“What interests and activities are most important to you?”



1. Interests & Activities

Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
1:	.	.	.
2:	.	.	.
3:	.	.	.

Planning Tool Guidance Document

“What’s the best way for you to stay close to and enjoy family and friends?”



2. Family, Friends & Others

Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
1:	.	.	.
2:	.	.	.
3:	.	.	.

Planning Tool Guidance Document

“What are your future plans for work, training and day activities?”



3. Work, Training & Day Activity

Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
1:	.	.	.
2:	.	.	.
3:	.	.	.

Planning Tool Guidance Document

“Think about where you want to live in the years ahead”



4. Living Arrangements

Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
1:	.	.	.
2:	.	.	.
3:	.	.	.

Planning Tool Guidance Document

“What kind of supports and care will you need in the future?”



5. Care & Support Arrangements

Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
1:	.	.	.
2:	.	.	.
3:	.	.	.

Planning Tool Guidance Document

“What legal arrangements need to be put in place to help organise your future plan?”



6. Legal Arrangements

Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
1:	.	.	.
2:	.	.	.
3:	.	.	.

Planning Tool Guidance Document

“What is the best way to arrange your finances?”



7. Financial Arrangements

Future Plans / Intentions	Supports & Resources Required	Actions Agreed	Person(s) Responsible
1:	.	.	.
2:	.	.	.
3:	.	.	.



Named Supports

As a named support person in this Future Care Road Map I agree to provide the support outlined in this document to the best of my ability.

[SUPPORT PERSON #1]

Signed _____ Date: _____

[SUPPORT PERSON #2]

Signed _____ Date: _____

[SUPPORT PERSON #3]

Signed _____ Date: _____

[SUPPORT PERSON #4]

Signed _____ Date: _____

[SUPPORT PERSON #5]

Signed _____ Date: _____

[SUPPORT PERSON #6]

Signed _____ Date: _____

[SUPPORT PERSON #7]

Signed _____ Date: _____

[SUPPORT PERSON #8]

Signed _____ Date: _____



The Trinity Centre for Ageing and Intellectual Disability (TCAID) aims to address the inequalities and health disparities that occur for people with intellectual disability as they age.

We do this by conducting rigorous engaged research on the physical and social determinants of health and wellbeing, and translating findings to inform models of policy and practice.



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